

New York State

**Children and Youth with Special Health Care Needs  
(CYSHCN)**

**Resource Guide**



# Welcome to the New York State Children and Youth with Special Health Care Needs (CYSHCN) Resource Directory!

This directory lists resources for children and youth with special health care needs (CYSHCN), as well as their advocates, caregivers, families, and providers. The New York State Department of Health (NYS DOH) defines CYSHCN as people from birth to 21 years old who require extra health care and support services because of developmental, emotional, intellectual, learning, medical and/or physical conditions. Resources in this directory are specific to the state of New York. The NYS DOH is committed to the well-being of CYSHCN and their support networks. If you have up-to-date information on a resource or if you would like to add a resource to this directory, please visit our Resource Referral Portal (<https://airtable.com/shrkMnVBdLJTryIVP>).

This directory is funded by the NYS DOH and the resources are maintained (through September 2024) by the three NYS University Centers for Excellence on Developmental Disabilities (UCEDDs). The three UCEDDs are as follows:



[The Rose F. Kennedy \(RFK\) Center at Einstein/Montefiore](#)



[The Strong Center at the University of Rochester](#)



[The Westchester Institute for Human Development \(WIHD\).](#)

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For more information on the New York State Department of Health Children and Youth with Special Health Care Needs (CYSHCN) Program, please visit: [https://www.health.ny.gov/community/special\\_needs/](https://www.health.ny.gov/community/special_needs/)

### **DISCLAIMER**

*The New York State Department of Health (NYSDOH)'s Children and Youth with Special Health Care Needs (CYSHCN) Program assembled this resource guide to enhance public access to information about human service resources available to New York residents. The inclusion of any organization, agency or service in this guide does not imply or constitute an endorsement or recommendation, nor does exclusion imply disapproval. The NYS DOH neither guarantees nor makes any representations as to the accuracy or completeness of the information contained in this resource guide. Furthermore, the NYSDOH does not claim responsibility for any actions taken by any of the organizations or agencies included in this resource guide. Under no circumstances shall the NYSDOH or its employees be liable for any direct, indirect, incidental, special, punitive or consequential damages which may result in any way from the use of the information included in the printed or online versions of this resource guide.*

**Children and Youth with Special Health Care Needs (CYSHCN)  
LOCAL HEALTH DEPARTMENTS**

	COUNTIES SERVED	RESOURCE
<b>FIND A LOCAL HEALTH DEPARTMENT</b>	ALL	<p><b>Local Health Departments</b>  <a href="https://www.health.ny.gov/community/special_needs/county_programs.htm">https://www.health.ny.gov/community/special_needs/county_programs.htm</a></p> <p>Local health departments (LHDs) help families of CYSHCN by giving them information on health insurance and connecting them with health care providers. These programs will also work with families to help them meet the medical and non-medical needs of their children.</p>
	Albany	<p><b>Albany County Department for Children, Youth &amp; Families</b>  <a href="https://www.albanycounty.com/departments/children-youth-and-families/children-with-special-needs">https://www.albanycounty.com/departments/children-youth-and-families/children-with-special-needs</a></p> <p>Programs for children with special health care needs perform various functions to assure that children up to the age of 21 with certain disabilities and/or chronic health conditions receive quality care while limiting the financial impact on families.</p>
	Allegany	<p><b>Allegany County Department of Health</b>  <a href="https://www.alleganyco.com/departments/health/childrens-programs">https://www.alleganyco.com/departments/health/childrens-programs</a></p> <p>The Children with Special Health Care Needs Program (CSHCN) program is an informational, referral and advocacy program for children from birth to 21 years of age who have, or are suspected of having a serious or chronic physical, developmental, behavioral, and/or emotional condition, and who require health or related services of a type of amount beyond that typically required of children.</p>
	Broome	<p><b>Broome County Department of Health</b>  <a href="http://gobroomecounty.com/hd/cshcn">http://gobroomecounty.com/hd/cshcn</a></p> <p>Through the Children with Special Health Care Needs program, assistance is given to families in finding appropriate community resources. Families are referred to community or state agencies to help them access health insurance and/or services for their children with special needs. Follow-up is offered to check on the need for further assistance. Outreach is provided within the community, including various community agencies, medical offices, daycare centers, preschools, and health fairs regarding services for children with special needs.</p>

	COUNTIES SERVED	RESOURCE
FIND A LOCAL HEALTH DEPARTMENT	Cattaraugus	<p><b>Cattaraugus County Department of Health</b>  <a href="https://www.cattco.org/health/services/children-families/special-needs">https://www.cattco.org/health/services/children-families/special-needs</a></p> <p>Families with physically disabled, cognitively challenged, or chronically ill children often need a wide range of services to meet their child's special needs. The CSHCN Program can help: link you with affordable health care; connect you with community programs; and, can answer questions about how to meet your child's needs.</p>
	Cayuga	<p><b>Cayuga County Department of Health</b>  <a href="https://www.cayugacounty.us/379/Children-with-Special-Health-Care-Needs">https://www.cayugacounty.us/379/Children-with-Special-Health-Care-Needs</a></p> <p>The Children with Special Health Care Needs program is a resource and referral program for children birth through age 21. The CSHCN program provides assistance to families who may need help accessing various health care professionals and other community resources.</p>
	Chautauqua	<p><b>Chautauqua County Department of Health</b>  <a href="http://www.co.chautauqua.ny.us/226/Early-Intervention-Program">http://www.co.chautauqua.ny.us/226/Early-Intervention-Program</a></p> <p>Children with Special Health Care Needs (CSHCN) is a referral linkage system to provide information to families of children, birth to 21 years of age, who have, or are suspected of having, a serious or chronic physical condition and require health-related services beyond those that are generally required by children. The goal of this program is to assist families who have children with special health care needs to obtain necessary health and community services.</p>
	Chemung	<p><b>Chemung County Health Department</b>  <a href="http://www.chemungcountyhealth.org/cshcn">http://www.chemungcountyhealth.org/cshcn</a></p> <p>Families with physically disabled, cognitively challenged or chronically ill children often need a wide range of services to meet their child's special needs: financial, medical, legal, educational, and emotional. Any child, ages birth to 21, who resides in New York State county who has or is suspected of having a serious or chronic physical, developmental, behavioral, or emotional condition that will require health and related services of a type or amount beyond that required by a typical child, is eligible to participate. CSHCN staff can assist families by providing useful information and making referrals to community and government resources that will help them provide for the needs of their child. Some counties also offer short-term case management and advocacy services on the child's behalf if needed.</p>

	COUNTIES SERVED	RESOURCE
FIND A LOCAL HEALTH DEPARTMENT	Chenango	<p><b>Chenango County Department of Health</b>  <a href="http://www.co.chenango.ny.us/public-health/children-with-special-needs">http://www.co.chenango.ny.us/public-health/children-with-special-needs</a></p> <p>This program provides services for children who have a developmental delay, disability, or condition. The division offers several programs designed to help families receive evaluation and treatment services.</p>
	Clinton	<p><b>Clinton County Department of Health</b>  <a href="http://www.clintonhealth.org/specialneeds">http://www.clintonhealth.org/specialneeds</a></p> <p>Children with Special Health Care Needs (CSHCN) are children 0-21 years of age that have, or are suspected of having a serious or chronic physical, developmental or emotional condition. This program is designed to improve the health and care needs of children who meet the eligibility criteria.</p>
	Columbia	<p><b>Columbia County Department of Health</b>  <a href="https://www.columbiacountynyhealth.com/programs-and-services/nursing-and-clinical-services">https://www.columbiacountynyhealth.com/programs-and-services/nursing-and-clinical-services</a></p> <p>The Columbia County Department of Health’s Children with Special Health Care Needs – CSHCN – is a program designed to provide information and guidance to families with a special needs child. A registered nurse is on staff to offer assistance with access to appropriate specialty care. Resource information and group support for a child’s particular condition is provided. The nurse may also assist with organizing your child’s medical history and records, help find transportation for medical appointments, and obtain translation services in Spanish or other languages.</p>
	Cortland	<p><b>Cortland County Department of Health</b>  <a href="https://www.cortland-co.org/474/Children-With-Special-Health-Care-Needs">https://www.cortland-co.org/474/Children-With-Special-Health-Care-Needs</a></p> <p>CSHCN is a referral program for children birth to 21 years of age who have or are suspected of having a serious or chronic physical, developmental behavioral, or emotional condition that requires health and related services beyond that required by children generally. Anyone can call for information and referral through CSHCN.</p>
	Delaware	<p><b>Delaware County Department of Health</b>  <a href="http://delawarecountypublichealth.com/programs/childrens-programs/special-healthcare-needs">http://delawarecountypublichealth.com/programs/childrens-programs/special-healthcare-needs</a></p> <p>The Children with Special Health Care Needs Program provides assistance to families of children with special health care needs birth through age 21 who need help in accessing various health care professionals and other community resources. We will also help you to access appropriate health care coverage such as Child Health Plus, Family Health Plus and Medicaid.</p>

	COUNTIES SERVED	RESOURCE
FIND A LOCAL HEALTH DEPARTMENT	Dutchess	<p><b>Dutchess County Department of Health</b>  <a href="https://www.dutchessny.gov/Departments/DBCH/Nursing-Services.htm">https://www.dutchessny.gov/Departments/DBCH/Nursing-Services.htm</a></p> <p>The Children With Special Health Care Needs Program is a referral service for families with health and related concerns. The Program refers children ages birth to 21 who are diagnosed or at risk for a developmental delay or disability that affects a child physically, behaviorally or intellectually; Is ongoing or chronic; and, requires health or health-related interventions beyond what a typical developing child would need.</p>
	Erie	<p><b>Erie County Department of Health</b>  <a href="https://www2.erie.gov/health/index.php?q=node/50">https://www2.erie.gov/health/index.php?q=node/50</a></p> <p>Early Intervention (EI) is a voluntary developmental evaluation and services program offered by New York State and administered locally by the Erie County Department of Health. The County EI Program is subject to NYS regulations. EI serves children from birth through 2 years of age and their families where there is a high risk of delay, a suspected delay in development, or a confirmed diagnosis of developmental disability. Evaluations are conducted to determine eligibility. A variety of therapeutic and support services are offered to eligible infants and toddlers with disabilities and their families. If a child is found not eligible, parents can request developmental monitoring.</p>
	Essex	<p><b>Essex County Department of Health</b>  <a href="https://www.co.essex.ny.us/Health/childrens-services">https://www.co.essex.ny.us/Health/childrens-services</a></p> <p>This program is for families of children ages birth to 21 who have or may have a serious health condition. The program gives information and referral services for families of children who need health or related services beyond those normally needed by children.</p>
	Franklin	<p><b>Franklin County Department of Health</b>  <a href="https://www.franklincountyny.gov/departments/human_services/public_health/services.php">https://www.franklincountyny.gov/departments/human_services/public_health/services.php</a></p> <p>The Children and Youth with Special Health Care Needs Program seeks to improve the system of care for children with special health care needs from birth to 21 years of age and their families. The Program helps to shape public policy so families can get the best health care for their children.</p>

	COUNTIES SERVED	RESOURCE
FIND A LOCAL HEALTH DEPARTMENT	Fulton	<p><b>Fulton County Department of Health</b>  <a href="https://www.fultoncountyny.gov/children-special-health-care-needs">https://www.fultoncountyny.gov/children-special-health-care-needs</a></p> <p>The Children with Special Health Care Needs Program seeks to improve the system of care for children with special health care needs from birth to 21 years of age and their families. Children served by the CSHCN Program have an illness or condition for which they need extra health care and support services. These children might have a serious or long-lasting physical condition, intellectual or developmental disability; and/or behavioral or emotional condition. This program is strictly a referral program. Services include information about health insurance, community resources, specialists and accessing health care providers. We also work with families to help them meet the medical and non-medical needs of their children.</p>
	Genesee	<p><b>Genesee County Department of Health</b>  <a href="http://co.genesee.ny.us/departments/health/children_with_special_health_care_needs.php">http://co.genesee.ny.us/departments/health/children_with_special_health_care_needs.php</a></p> <p>This program is an informational, referral and advocacy program for children from birth to 21 years of age who may require health or related services, of a type or amount, beyond that typically required by children. Program assistance does not require eligibility or fees in order to obtain services. Case Management services, funded by the Children with Special Health Care Needs Grant, offer outreach and referral to connect families with appropriate services. We want to help you help your child reach his or her full potential.</p>
	Greene	<p><b>Greene County Public Health</b>  <a href="https://www.greenegovernment.com/departments/public-health/childrens-programs/special-health-care-needs-program">https://www.greenegovernment.com/departments/public-health/childrens-programs/special-health-care-needs-program</a></p> <p>The Children with Special Health Care Needs Program is an information and referral service. We provide assistance to families of children with special health care needs from birth to age 21. Raising a child with special health care needs can be challenging. It can be difficult to identify what services are available to you and to your child. Please contact us with any questions you may have about the Children with Special Health Care Needs Program so we can provide assistance at no cost to your family.</p>



	COUNTIES SERVED	RESOURCE
FIND A LOCAL HEALTH DEPARTMENT	Hamilton	<p><b>Hamilton County Department of Health</b>  <a href="https://www.hamiltoncounty.com/health-human-services/public-health-home/family-health-services">https://www.hamiltoncounty.com/health-human-services/public-health-home/family-health-services</a></p> <p>Children served by the CSHCN Program have an illness or condition for which they need extra health care and support services. These children might have a serious or long-lasting physical condition, intellectual or developmental delay, and/or behavioral or emotional condition. HCPHNS supports families of children with special health care needs by giving them information on health insurance and connecting them with health care providers and programs.</p>
	Herkimer	<p><b>Herkimer County Public Health</b>  <a href="https://www.herkimercounty.org/services-and-departments/public-health.php">https://www.herkimercounty.org/services-and-departments/public-health.php</a></p> <p>The Herkimer County Public Health team is dedicated to the protection and promotion of our resident's health through the provision of high quality, comprehensive, individualized services, in all phases of the life cycle. Available programs for children with special needs include Early Intervention, Child Find, and Pre-School Special Education.</p>
	Jefferson	<p><b>Jefferson County Department of Health</b>  <a href="https://co.jefferson.ny.us/departments/PublicHealth/cshcn-phcp">https://co.jefferson.ny.us/departments/PublicHealth/cshcn-phcp</a></p> <p>CSHCN serves children from birth to 21 years of age who have (or may have) a serious or chronic physical, developmental, behavioral, or emotional condition. The Program provides: assistance in locating a physician or other health care provider; assistance in obtaining insurance and other programs that cover health care costs; assistance in finding other help and support such as home care, parents support groups, and information about medical conditions; and, care coordination services that assist families to access the various services available.</p>
	Lewis	<p><b>Lewis County Public Health</b>  <a href="https://www.lewiscounty.org/departments/public-health/children-with-special-needs">https://www.lewiscounty.org/departments/public-health/children-with-special-needs</a></p> <p>Children with Special Care Needs (CSCN) Programs assist children from birth to age 21 to reach toward and achieve developmental and educational goals. We can assist with accessing health and non-health care services. We can help with obtaining insurance, educational resources, social program assistance (public health services, social services, WIC, food stamps, SSI, transportation, respite services), and medical equipment.</p>

	COUNTIES SERVED	RESOURCE
FIND A LOCAL HEALTH DEPARTMENT	Livingston	<p><b>Livingston County Department of Health</b>  <a href="https://www.livingstoncounty.us/1157/Children-with-Special-Healthcare-Needs-P">https://www.livingstoncounty.us/1157/Children-with-Special-Healthcare-Needs-P</a></p> <p>The Children with Special Healthcare Needs Program administered by the Livingston County Department of Health focuses on children ages 0-21 who have, or are suspected of having a serious or chronic condition that also requires services of a type or amount beyond what is required generally. Key activities of the program include disseminating Child Health Plus information and facilitating access to health care coverage for children who are uninsured or under-insured.</p>
	Madison	<p><b>Madison County Department of Health</b>  <a href="https://www.madisoncounty.ny.gov/445/Children-With-Special-Healthcare-Needs">https://www.madisoncounty.ny.gov/445/Children-With-Special-Healthcare-Needs</a></p> <p>The Children with Special Health Care Needs Program assists families of children birth to 21 years who have or are suspected of having a serious or chronic physical, developmental, or emotional condition. Information and referral services are provided to help the family access community resources as well as appropriate health care. The Program helps families of children under 21 years to access available community resources and services; assists families with health insurance needs; and, provides information and referrals regarding disability and health topics. Services are free of charge to families.</p>
	Monroe	<p><b>Monroe County Department of Health</b>  <a href="https://www2.monroecounty.gov/health-maternal-children-health-needs">https://www2.monroecounty.gov/health-maternal-children-health-needs</a></p> <p>The Children with Special Health Care Needs Program (CSHCN) is a statewide public health program that provides information and referral services for health and related areas for families of CSHCN. The CSHCN Program provides families with information and referrals to fit their child’s growing needs. Children who are enrolled in the Early Intervention Program can continue to receive help through CSHCN when they “age out” of Early Intervention.</p>
	Montgomery	<p><b>Montgomery County Department of Health</b>  <a href="https://www.co.montgomery.ny.us/web/sites/departments/publichealth">https://www.co.montgomery.ny.us/web/sites/departments/publichealth</a></p> <p>The Children with Special Health Care Needs Program (CSHCN) is a statewide referral system of care for children and their families, linking them to appropriate health and related services to identify and resolve gaps and barriers, and to assure access to quality health care. For all children from birth to 21 years of age who have an identified disability, the following services are available: connect families with community resources and programs; provide support and guidance Information about children with special needs, illness, and disability; research additional resources not available to the family; address concerns and required health or related services beyond what children generally need; employ state tracking system to identify gaps in services for children with special health care needs.</p>

	COUNTIES SERVED	RESOURCE
FIND A LOCAL HEALTH DEPARTMENT	Nassau	<p><b>Nassau County Department of Health</b>  <a href="https://nassaucountyny.gov/3666/Children-Youth">https://nassaucountyny.gov/3666/Children-Youth</a></p> <p>The Children with Special Health Care Needs Program (CSHCN) in Nassau County can be contacted by calling 516-227-8665.</p>
	New York City (Bronx/Kings/New York/Richmond/Queens)	<p><b>New York City Department of Health and Mental Hygiene</b>  <a href="https://www1.nyc.gov/site/doh/health/health-topics/children-with-special-healthcare-needs.page">https://www1.nyc.gov/site/doh/health/health-topics/children-with-special-healthcare-needs.page</a></p> <p>Children with Special Health Care Needs is a program that provides information as well as referrals to health services and community resources for children with special needs. This program also helps families apply for low or no-cost health insurance. The program can help families with: applying for low- or no-cost health insurance; finding free medical evaluations and low-cost health services in your community; locating medical providers who can examine your child and develop an individual care plan; and, finding referrals to medical specialists who can care for children with complex needs.</p>
	Niagara	<p><b>Niagara County Department of Health</b>  <a href="https://www.niagaracounty.com/health/Services/Children-With-Special-Needs/Children-With-Special-Health-Care-Needs">https://www.niagaracounty.com/health/Services/Children-With-Special-Needs/Children-With-Special-Health-Care-Needs</a></p> <p>The Children with Special Health Care Needs Program assists families who have children that have a chronic physical, developmental, behavioral or emotional condition, and require health and related services of a type or amount beyond that required by children generally. The Program assists the family through information and referral to various community resources that are child and family specific.</p>
	Oneida	<p><b>Oneida County Department of Health</b>  <a href="https://www.ocgov.net//oneida/health/programservices">https://www.ocgov.net//oneida/health/programservices</a></p> <p>Children and Youth with Special Health Care Needs is a referral program for children birth to 21 years of age who have or are suspected of having a serious or chronic physical, developmental, behavioral or emotional condition that requires health and related services beyond that required by children generally. Services include: helping coordinate referrals to specialty care providers; providing limited case management; facilitating access to health insurance, such as Child Health Plus and Medicaid; and, providing information and referrals to appropriate programs.</p>

	COUNTIES SERVED	RESOURCE
FIND A LOCAL HEALTH DEPARTMENT	Onondaga	<p><b>Onondaga County Health Department</b>  <a href="http://www.ongov.net/health/SCS.html">http://www.ongov.net/health/SCS.html</a></p> <p>The Onondaga County Health Department’s Special Children Services provides evaluations, education, and therapy for children up to age five who have a developmental delay or disability. Programs include Early Intervention and Preschool Special Education.</p>
	Ontario	<p><b>Ontario County Department of Health</b>  <a href="https://www.co.ontario.ny.us/632/Children-with-Special-Needs-Program">https://www.co.ontario.ny.us/632/Children-with-Special-Needs-Program</a></p> <p>The Children With Special Health Care Needs (CSHCN) Program focuses on children ages 0-21 who have, or are suspected of having, a serious or chronic physical, developmental, behavioral, or emotional condition and who also require services of a type or amount beyond that required by children generally. The Bureau of Child and Adolescent Health hopes that by creating this program it will better define the issues and priorities of this population. Key activities for this program include: disseminating Child Health Plus information and facilitating access to health care coverage for CSHCN's who are uninsured or under-insured; reporting on contacts made to the program.</p>
	Orange	<p><b>Orange County Department of Health</b>  <a href="https://www.orangecountygov.com/774/Children-with-Special-Health-Care-Needs">https://www.orangecountygov.com/774/Children-with-Special-Health-Care-Needs</a></p> <p>The Children with Special Health Care Needs Program is an information and referral service designed to assist the families of physically challenged or chronically ill children from birth through age 21 years. Our staff will help to coordinate specialty care, provide information about programs and resources appropriate for your child with special needs. We will assist families to locate community based services such as Health Navigators/NYS of Health Marketplace at 800-453-4666 and Medicaid, Early Intervention, Women, Infants and Children (WIC), Developmental Disabilities Service Office (DDSO) and other parent supports.</p>
	Orleans	<p><b>Orleans County Department of Health</b>  <a href="https://gohealthny.org/children-with-special-needs/">https://gohealthny.org/children-with-special-needs/</a></p> <p>The Orleans County Public Health Department conducts programs that are shown to effectively make communities healthier, including the Children with Special Needs Program. Services are provided through free resources &amp; referrals, public programs, speakers, in-service trainings, social media, etc.</p>

	COUNTIES SERVED	RESOURCE
FIND A LOCAL HEALTH DEPARTMENT	Oswego	<p><b>Oswego County Department of Health</b>  <a href="https://health.oswegocounty.com/programs/1_children_with_special_needs/index.php">https://health.oswegocounty.com/programs/1_children_with_special_needs/index.php</a></p> <p>As your child with special needs travels through the many phases of his or her life, the Oswego County Health Department-Children with Special Needs Division hopes you will find comfort in knowing there is a whole team of professionals who are here to help. We can guide you through the sometimes confusing educational and health care systems, and help you find the services that best suit your family's needs. Our service coordinators provide one-on-one services to determine the best course of action for you and your family.</p>
	Otsego	<p><b>Otsego County Health Department</b>  <a href="https://www.otsegocounty.com/departments/children_with_special_needs/index.php">https://www.otsegocounty.com/departments/children_with_special_needs/index.php</a></p> <p>The Otsego County Health Department offers the following programs for children with special needs: Early Intervention, Preschool Special Education, and Evaluation and Education Services.</p>
	Putnam	<p><b>Putnam County Department of Health</b>  <a href="https://www.putnamcountyny.com/health/child">https://www.putnamcountyny.com/health/child</a></p> <p>The Putnam County Department of Health offers the following programs for children with special needs: Early Intervention, Preschool Special Education, and Child Find, which seeks to improve the identification of infants and children ages 0-3 at risk for developmental delays and disabilities and to ensure their referral to care, follow-up and monitoring.</p>
	Rensselaer	<p><b>Rensselaer County Department of Health</b>  <a href="https://www.rensco.com/departments/public-health/children-with-special-needs">https://www.rensco.com/departments/public-health/children-with-special-needs</a></p> <p>Children with special health care needs are children birth to 21 years of age who have or are suspected of having a serious or chronic physical, developmental, behavioral or emotional condition. Also, under this are children who require special health or related services beyond that is required by children generally. Our Child Services Specialists can assist families with providing support and resources to access services to improve the quality of life for their Children with Special Health Care Needs and their families.</p>

	COUNTIES SERVED	RESOURCE
FIND A LOCAL HEALTH DEPARTMENT	Rockland	<p><b>Rockland County Department of Health</b>  <a href="http://rocklandgov.com/departments/health/programs-and-services/children-with-special-needs-programs">http://rocklandgov.com/departments/health/programs-and-services/children-with-special-needs-programs</a></p> <p>The Children with Special Health Care Needs Program (CYSHCN) is an effort to positively impact the lives of children and youth with special health care needs and their families by providing resources needed to access appropriate services. Through the coordination and delivery of medical, educational, and related services identified needs of the child and family are met, thus enhancing the child's quality of life. CYSHCN assists families with children from birth to twenty-one (21) years of age that have a chronic physical, developmental, behavioral, or emotional condition and require health and related services beyond that generally required by children. The program assists the family through information and referral to various community resources that are child and family specific. Rockland County Department of Health staff can connect your family to support networks that understand the challenges of caring for children and youth with special needs.</p>
	Saratoga	<p><b>Saratoga County Public Health Services</b>  <a href="https://www.saratogacountyny.gov/departments/publichealth/children-with-special-health-care-needs-cshcn">https://www.saratogacountyny.gov/departments/publichealth/children-with-special-health-care-needs-cshcn</a></p> <p>Children and Youth with Special Health Care Needs (CYSHCN) are those from birth to age 21 who require health care or related services beyond regular well care and preventive measures to keep children healthy. CYSHCN is a New York State Department of Health initiative designed to provide information, guidance and referrals to families with a special needs child.</p>
	Schenectady	<p><b>Schenectady County Department of Health</b>  <a href="https://www.schenectadycounty.com/CWSN">https://www.schenectadycounty.com/CWSN</a></p> <p>The Children with Special Health Care Needs Program (CSHCN) is a statewide public health program that provides information and referral services for health and related areas for families of CSHCN. This program is a referral linkage system to provide for those children ages birth to 21 who have, or are suspected of having, a serious or chronic physical, developmental, behavioral, or emotional condition and who require a health or related service of a type or amount beyond what is required by children generally.</p>

	COUNTIES SERVED	RESOURCE
FIND A LOCAL HEALTH DEPARTMENT	Schoharie	<p><b>Schoharie County Public Health</b>  <a href="https://www4.schohariecounty-ny.gov/departments/public-health/preschool">https://www4.schohariecounty-ny.gov/departments/public-health/preschool</a></p> <p>Schoharie County Public Health has programs for children with special needs that include preschool and early intervention referrals as well as Child Find, a component of the Early Intervention Program that assures that children at-risk (birth-3 years) will receive the help needed for the best growth and development in the early years. Child Find ensures tracking and screening of children at-risk of developmental delay through ongoing contact with families and the primary care provider. This program can provide direct developmental screenings when no other resource is available.</p>
	Schuyler	<p><b>Schuyler County Public Health</b>  <a href="http://www.schuylercounty.us/622/Children-with-Special-Health-Care-Needs">http://www.schuylercounty.us/622/Children-with-Special-Health-Care-Needs</a></p> <p>Schuyler County Public Health seeks to improve the system of care for all children and their families. Our goal is to help shape public policy so families can get the best health care for their children including those who have health concerns or delays which require extra support and services. The Children with Special Health Care Needs Program serves children and their families from birth to 21 years of age who have long term conditions that require support.</p>
	Seneca	<p><b>Seneca County Department of Health</b>  <a href="https://www.co.seneca.ny.us/gov/services/family-services">https://www.co.seneca.ny.us/gov/services/family-services</a></p> <p>Seneca County Human Services, in collaboration with the community, provides access to resources, promotes equal opportunities, and empowers individuals and families toward greater self-sufficiency and improved quality of life. The employees of the Division provide these services with integrity, competence, and respect to diversity.</p>
	St. Lawrence	<p><b>St. Lawrence County Department of Health</b>  <a href="https://www.stlawco.org/Departments/PublicHealth/ChildrenSpecialHealthCareNeeds">https://www.stlawco.org/Departments/PublicHealth/ChildrenSpecialHealthCareNeeds</a></p> <p>The Children With Special Health Care Needs Program provides assistance in locating a physician or other health care provider to ensure each child has a medical home. The program may also provide assistance in obtaining insurance and/or other programs that help to cover health care costs – i.e. Medicaid, Child Health Plus. Supportive measures as well as medical information may be provided.</p>

	COUNTIES SERVED	RESOURCE
FIND A LOCAL HEALTH DEPARTMENT	Steuben	<p><b>Steuben County Department of Health</b>  <a href="https://www.steubencony.org/pages.asp?PID=178">https://www.steubencony.org/pages.asp?PID=178</a></p> <p>The Children with Special Health Care Needs Program provides information and referral services for health and related topics to families of children, from birth to 21 years of age. Any family that has children who have, or are suspected of having, a serious or chronic healthcare condition is eligible for information and referral services at no cost.</p>
	Suffolk	<p><b>Suffolk County Department of Health</b>  <a href="https://www.suffolkcountyny.gov/Departments/Health-Services/Children-With-Special-Needs">https://www.suffolkcountyny.gov/Departments/Health-Services/Children-With-Special-Needs</a></p> <p>The Children with Special Health Care Needs Program performs various functions to assure that children up to the age of 21 with certain disabilities and/or chronic health conditions receive quality care while limiting the financial impact on families. Service coordinators provide case management to empower families to meet challenges of caring for a child with special health care needs and assist families in accessing educational services, as well as community resources.</p>
	Sullivan	<p><b>Sullivan County Public Health Services</b>  <a href="http://sullivanny.us/Departments/Publichealth/Childrenwithspecialhealthcareneeds">http://sullivanny.us/Departments/Publichealth/Childrenwithspecialhealthcareneeds</a></p> <p>The Children with Special Health Care Needs Program (CSHCN) includes three programs: the Early Intervention Program (ages 0-3), the Preschool Special Education Program (ages 3-5), and the Children and Youth with Special Health Care Needs Supportive Services (CYSHCN-SS up to age 21).</p>
	Tioga	<p><b>Tioga County Department of Health</b>  <a href="https://www.tiogacountyny.com/departments/public-health">https://www.tiogacountyny.com/departments/public-health</a></p> <p>The Children with Special Health Care Needs (CSHCN) program is an informational referral and advocacy program for children birth to 21 years who have, or are suspected of having, a serious or chronic physical, developmental, behavioral, and/or emotional condition, and require health or related services of a type or amount beyond that typically required of children. This program can help families: make referrals for special health care or related services; obtain information on programs and services available in the community; increase knowledge regarding available resources; navigate through Preschool Special Education process (for children ages 3-5); and, obtain family support services.</p>



	COUNTIES SERVED	RESOURCE
FIND A LOCAL HEALTH DEPARTMENT	Tompkins	<p><b>Tompkins County Health Department</b>  <a href="http://tompkincountyny.gov/health/cscn#CSCN">http://tompkincountyny.gov/health/cscn#CSCN</a></p> <p>The Children with Special Health Care Needs Program provides assistance to families of children with special health care needs birth through age 21 who need help in accessing various health care professionals and other community resources. We will also help you to access appropriate health care coverage such as Child Health Plus, Family Health Plus and Medicaid. Our Family Outreach Worker is a Certified Social Worker who will work one-on-one with you to help you meet your family's needs.</p>
	Ulster	<p><b>Ulster County Department of Health</b>  <a href="http://ulstercountyny.gov/health/divisions/patient-services-division">http://ulstercountyny.gov/health/divisions/patient-services-division</a></p> <p>The Children with Special Health Care Needs Program ensures access to quality health care for children who are chronically ill and/or have disabilities.</p>
	Warren	<p><b>Warren County Department of Health</b>  <a href="https://warrencountyny.gov/healthservices/children">https://warrencountyny.gov/healthservices/children</a></p> <p>The Children and Youth with Special Healthcare Needs Program (CYSHCN) is a state wide public health program that provides information and referral services for health and related areas for families of CYSHCN. Warren County's CYSHCN program provides case management services as needed. The CYSHCN assists families in paying medical bills for children with severe chronic illnesses and/or disabilities, between birth and 21 years of age, who live in New York State and meet medical and financial eligibility requirements.</p>
	Washington	<p><b>Washington County Health Department</b>  <a href="https://washingtoncountyny.gov/299/Public-Health-Services">https://washingtoncountyny.gov/299/Public-Health-Services</a></p> <p>Washington County Public Health Services offers the following programs for children with special needs: Child Find, Early Intervention, and Preschool Program for Children with Disabilities.</p>

	COUNTIES SERVED	RESOURCE
FIND A LOCAL HEALTH DEPARTMENT	Wayne	<p><b>Wayne County Department of Health</b>  <a href="https://web.co.wayne.ny.us/index.php/publichealth/ichap-child-find">https://web.co.wayne.ny.us/index.php/publichealth/ichap-child-find</a></p> <p>Our Children With Special Health Care Needs program ensures access to quality care for chronically ill or disabled children who meet the financial eligibility requirements. It offers help with diagnosis, evaluation and treatment programs for those who qualify.</p>
	Westchester	<p><b>Westchester County Department of Health</b>  <a href="https://health.westchestergov.com/children-with-special-health-care-needs-program-cshcn">https://health.westchestergov.com/children-with-special-health-care-needs-program-cshcn</a></p> <p>Children with Special Health Care Needs (CSHCN) is an information and referral service for families with children with special needs from birth through 21 years of age. CSHCN staff work with families to ensure that children in need of special services are able to receive them without undue financial hardship. Staff members in the Children with Special Needs division of the Health Department can provide guidance on access to care, and refer families to the department's Facilitated Enrollment Program for access to programs including Child Health Plus A and Child Health Plus B enrollment outreach.</p>
	Wyoming	<p><b>Wyoming County Youth Bureau</b>  <a href="http://www.wyomingco.net/263/Children-with-Special-Health-Care-Needs">http://www.wyomingco.net/263/Children-with-Special-Health-Care-Needs</a></p> <p>The Children with Special Health Care Needs (CSHCN) Program is a public health program that provides information and referral services in health and related areas for families of CSHCN are those children from birth to 21 years of age who have or are suspected of having a serious or chronic developmental, physical, behavioral or emotional condition and who also require health and related services of a type or amount beyond that typically required by children. The CSHCN can help: link families to community resources and programs to assist them in caring or their child; provide support and guidance with issues such as equipment, education, respite care, insurance and health care financing; and, connect families to appropriate support groups and networks.</p>
	Yates	<p><b>Yates County Department of Health</b>  <a href="https://www.yatescounty.org/213/Children-Services">https://www.yatescounty.org/213/Children-Services</a></p> <p>The Children with Special Health Care Needs (CSHCN) Program focuses on children birth to age 21. Information, referrals and advocacy for children who may require health or related services of a type or amount beyond that typically required by children. Case management is a free service under this program, offering outreach and referral to connect families with appropriate services.</p>

**Children and Youth with Special Health Care Needs (CYSHCN)  
INDIVIDUAL RESOURCE PROFILES**

# Access: Supports for Living



Regional Resource Guide  
of the Children and Youth with Special  
Health Care Needs (CYSHCN) Project

**Agency Name:** Access: Supports for Living

**Agency Description:** Our mission is to help people live the healthiest and fullest lives possible, and our first priority is those who live with the challenges associated with developmental disabilities and behavioral health issues. We offer service coordination, Early Intervention (EI), and family assistance support for services in the home for the medically fragile children.

**Phone Number:** (845) 692-4454

**Email Address:** [info@asfl.org](mailto:info@asfl.org)

**Website:** <http://accessupports.org/>

**Counties Served:** Dutchess County Greene County Orange County

**Content Categories:** Accessibility & Assistive Technology Care Coordination Community Living & Recreation Early Childhood & School Aged Family & Supports Financial, Legal & Advocacy Information & Referral Medical, Dental & Behavioral Health Transitioning to Adulthood (Youth)

**Conditions Covered:** Allergies Anxiety Asthma Blood Disorders Cerebral Palsy (CP) Cystic Fibrosis (CF) Depression Developmental Delay Diabetes Down Syndrome Genetic or Inherited Condition Brain Injury, Concussion, or Head Injury Deafness or Problems with Hearing Heart Condition Intellectual Disability Learning Difficulty Migraines Other Mental Health Condition Speech or Language Disorder Spina Bifida Substance Use Disorder Tourette Syndrome (TS) Blindness or Problems with Seeing Other Attention-Deficit/Hyperactivity Disorder (ADHD) Arthritis Autism Spectrum Disorder (ASD) Behavioral / Conduct Problem Epilepsy / Seizure Disorder

# Active Minds



Regional Resource Guide  
of the Children and Youth with Special  
Health Care Needs (CYSHCN) Project

**Agency Name:** Active Minds

**Agency Description:** We are dedicated to saving lives and to building stronger families and communities. Through education, research, advocacy, and a focus on young adults ages 14–25, Active Minds is opening up the conversation about mental health and creating lasting change in the way mental health is talked about, cared for, and valued in the United States.

**Phone Number:** (202) 332-9595

**Email Address:** [info@activeminds.org](mailto:info@activeminds.org)

**Website:** <http://www.activeminds.org/>

**Counties Served:** State-Wide

**Content Categories:** Family & Supports Information & Referral Transitioning to Adulthood (Youth) Community Living & Recreation  
Financial, Legal & Advocacy Medical, Dental & Behavioral Health

**Conditions Covered:** Anxiety Behavioral / Conduct Problem Depression Other Mental Health Condition  
Brain Injury, Concussion, or Head Injury Substance Use Disorder

# ADDitude Magazine



Regional Resource Guide  
of the Children and Youth with Special  
Health Care Needs (CYSHCN) Project

**Agency Name:** ADDitude Magazine

**Agency Description:** ADDitude is required reading for anyone touched by ADHD — plain & simple. The nation's leading source of important news, expert advice, and judgment-free understanding for families and adults living with attention deficit disorder. ADDitude is your voice and your advocate. Subscriptions vary in price but you also can read free online on their website.

**Phone Number:** (646) 366-0830

**Email Address:** [customerservice@additudemag.com](mailto:customerservice@additudemag.com)

**Website:** <http://www.additudemag.com/>

**Counties Served:** State-Wide

**Content Categories:** Early Childhood & School Aged Accessibility & Assistive Technology Family & Supports Information & Referral My Child's Condition: Disability Specific Reference Community Living & Recreation Financial, Legal & Advocacy Transitioning to Adulthood (Youth)

**Conditions Covered:** Attention-Deficit/Hyperactivity Disorder (ADHD)

# Adoptive and Foster Family Coalition of New York (AFFCNY)



Regional Resource Guide  
of the Children and Youth with Special  
Health Care Needs (CYSHCN) Project

**Agency Name:** Adoptive and Foster Family Coalition of New York (AFFCNY)

**Agency Description:** The Adoptive and Foster Family Coalition of New York (AFFCNY) unites foster, adoptive and kinship care families, giving them a voice and providing support, information and advocacy. AFFCNY offers resources on health, disabilities and special needs.

**Phone Number:** (646) 688-4321

**Email Address:** [info@affcny.org](mailto:info@affcny.org)

**Website:** <http://affcny.org/family-supports/health-disabilities-and-special-needs/>

**Counties Served:** State-Wide

**Content Categories:** Family & Supports Financial, Legal & Advocacy Information & Referral

**Conditions Covered:** Allergies Anxiety Arthritis Asthma Attention-Deficit/Hyperactivity Disorder (ADHD) Autism Spectrum Disorder (ASD) Behavioral / Conduct Problem Blood Disorders Brain Injury, Concussion, or Head Injury Cerebral Palsy (CP) Cystic Fibrosis (CF) Depression Developmental Delay Diabetes Down Syndrome Epilepsy / Seizure Disorder Genetic or Inherited Condition Deafness or Problems with Hearing Heart Condition Intellectual Disability Learning Difficulty Migraines Other Other Mental Health Condition Speech or Language Disorder Spina Bifida Substance Use Disorder Tourette Syndrome (TS) Blindness or Problems with Seeing

# Adult Career and Continuing Education Services: Vocational Rehabilitation (ACCES-VR)



Regional Resource Guide  
of the Children and Youth with Special  
Health Care Needs (CYSHCN) Project

**Agency Name:** Adult Career and Continuing Education Services: Vocational Rehabilitation (ACCES-VR)

**Agency Description:** Adult Career and Continuing Education Services-Vocational Rehabilitation (ACCES-VR) assists individuals with disabilities to achieve and maintain employment and to support independent living through training, education, rehabilitation, and career development. Vocational Rehabilitation Counselors guide individuals through service programs they need to reach their employment goal.

**Phone Number:** (800) 222-5627

**Email Address:**

**Website:** <http://www.acces.nysed.gov/vr>

**Counties Served:** State-Wide

**Content Categories:** Transitioning to Adulthood (Youth) Government Agency

**Conditions Covered:** Attention-Deficit/Hyperactivity Disorder (ADHD) Anxiety Arthritis Autism Spectrum Disorder (ASD) Asthma Behavioral / Conduct Problem Cerebral Palsy (CP) Cystic Fibrosis (CF) Depression Developmental Delay Down Syndrome Epilepsy / Seizure Disorder Genetic or Inherited Condition Brain Injury, Concussion, or Head Injury Deafness or Problems with Hearing Intellectual Disability Other Mental Health Condition Speech or Language Disorder Spina Bifida Substance Use Disorder Tourette Syndrome (TS) Blindness or Problems with Seeing Other Learning Difficulty



# Advance Care Alliance of New York (ACA/NY)



Regional Resource Guide  
of the Children and Youth with Special  
Health Care Needs (CYSHCN) Project

**Agency Name:** Advance Care Alliance of New York (ACA/NY)

**Agency Description:** Advance Care Alliance of New York (ACA/NY) is a non-profit organization that is one of seven New York State Care Coordination Organizations (CCO) designated by the New York State Department of Health and the Office for People With Developmental Disabilities (OPWDD) to offer comprehensive care coordination to people with intellectual and/or developmental disabilities (I/DD).

**Phone Number:** (833) 692-2269

**Email Address:** [questions@myacany.org](mailto:questions@myacany.org)

**Website:** <http://acany.org/>

## Counties Served:

Bronx County (The Bronx - NYC) Kings County (Brooklyn - NYC) New York County (Manhattan - NYC)  
Queens County (Queens - NYC) Richmond County (Staten Island - NYC) Nassau County Orange County  
Rensselaer County Rockland County Suffolk County Westchester County

## Content Categories:

Care Coordination Government Agency Information & Referral Family & Supports Transitioning to Adulthood (Youth)  
Medical, Dental & Behavioral Health Early Childhood & School Aged

## Conditions Covered:

Allergies Anxiety Arthritis Asthma Attention-Deficit/Hyperactivity Disorder (ADHD) Autism Spectrum Disorder (ASD)  
Behavioral / Conduct Problem Blood Disorders Brain Injury, Concussion, or Head Injury Cerebral Palsy (CP)  
Cystic Fibrosis (CF) Depression Developmental Delay Diabetes Down Syndrome Epilepsy / Seizure Disorder  
Genetic or Inherited Condition Deafness or Problems with Hearing Heart Condition Intellectual Disability  
Learning Difficulty Migraines Other Mental Health Condition Speech or Language Disorder Spina Bifida  
Substance Use Disorder Tourette Syndrome (TS) Blindness or Problems with Seeing

**Agency Name:** AIM Services, Inc

**Agency Description:** AIM Services, Inc. is a non-profit organization providing residential and community-based services to people with disabilities, including those with traumatic brain injuries and those who are looking for nursing home transition or diversion. We provide all of our services in Saratoga, Warren, and Washington County. Our self direction program provides services in additional areas; Capital District, Long Island, Taconic, Hudson, and Sunmount regions.

**Phone Number:** (518) 587-3208

**Email Address:** [aimservices@aimservicesinc.org](mailto:aimservices@aimservicesinc.org)

**Website:** <http://www.aimservicesinc.org/>

**Counties Served:** [Warren County](#) [Saratoga County](#) [Washington County](#)

**Content Categories:** [Accessibility & Assistive Technology](#) [Care Coordination](#) [Community Living & Recreation](#) [Early Childhood & School Aged](#) [Family & Supports](#) [Financial, Legal & Advocacy](#) [Information & Referral](#) [Medical, Dental & Behavioral Health](#) [Transitioning to Adulthood \(Youth\)](#) [My Child's Condition: Disability Specific Reference](#)

**Conditions Covered:** [Allergies](#) [Anxiety](#) [Asthma](#) [Blood Disorders](#) [Cerebral Palsy \(CP\)](#) [Cystic Fibrosis \(CF\)](#) [Depression](#) [Developmental Delay](#) [Diabetes](#) [Down Syndrome](#) [Genetic or Inherited Condition](#) [Brain Injury, Concussion, or Head Injury](#) [Deafness or Problems with Hearing](#) [Heart Condition](#) [Intellectual Disability](#) [Learning Difficulty](#) [Migraines](#) [Other Mental Health Condition](#) [Speech or Language Disorder](#) [Spina Bifida](#) [Substance Use Disorder](#) [Tourette Syndrome \(TS\)](#) [Blindness or Problems with Seeing](#) [Other](#) [Attention-Deficit/Hyperactivity Disorder \(ADHD\)](#) [Arthritis](#) [Autism Spectrum Disorder \(ASD\)](#) [Behavioral / Conduct Problem](#) [Epilepsy / Seizure Disorder](#)

# American Academy of Developmental Medicine & Dentistry (AADMD)



Regional Resource Guide  
of the Children and Youth with Special  
Health Care Needs (CYSHCN) Project

**Agency Name:** American Academy of Developmental Medicine & Dentistry (AADMD)

**Agency Description:** To provide a forum for healthcare professionals who provide clinical care to people with intellectual & developmental disabilities (IDD) and improve the quality of healthcare for individuals with IDD.

**Phone Number:** (479) 200-3030

**Email Address:**

**Website:** <http://www.aadmd.org/>

**Counties Served:** State-Wide

**Content Categories:** Medical, Dental & Behavioral Health Information & Referral

**Conditions Covered:** Developmental Delay Intellectual Disability

# American Academy of Pediatric Dentistry (AAPD): Pediatric Dentist Search



Regional Resource Guide  
of the Children and Youth with Special  
Health Care Needs (CYSHCN) Project

**Agency Name:** American Academy of Pediatric Dentistry (AAPD): Pediatric Dentist Search

**Agency Description:** The American Academy of Pediatric Dentistry (AAPD) is the recognized authority on children's oral health. As advocates for children's oral health, the AAPD promotes evidence-based policies and clinical guidelines; educates and informs policymakers, parents and guardians, and other health care professionals; fosters research; and provides continuing professional education for pediatric dentists and general dentists who treat children. Its members provide primary care and comprehensive dental specialty treatments for infants, children, adolescents and individuals with special health care needs

**Phone Number:** (312) 337-2169

**Email Address:**

**Website:** <http://www.mychildrensteeth.org/>

**Counties Served:** State-Wide

**Content Categories:** Information & Referral Medical, Dental & Behavioral Health Financial, Legal & Advocacy

**Conditions Covered:** Attention-Deficit/Hyperactivity Disorder (ADHD) Allergies Anxiety Arthritis Autism Spectrum Disorder (ASD) Asthma Behavioral / Conduct Problem Blood Disorders Cerebral Palsy (CP) Cystic Fibrosis (CF) Depression Developmental Delay Diabetes Down Syndrome Epilepsy / Seizure Disorder Genetic or Inherited Condition Brain Injury, Concussion, or Head Injury Deafness or Problems with Hearing Heart Condition Intellectual Disability Migraines Other Mental Health Condition Speech or Language Disorder Spina Bifida Substance Use Disorder Tourette Syndrome (TS) Blindness or Problems with Seeing Other Learning Difficulty

# American Association of People with Disabilities (AAPD)



Regional Resource Guide  
of the Children and Youth with Special  
Health Care Needs (CYSHCN) Project

**Agency Name:** American Association of People with Disabilities (AAPD)

**Agency Description:** The American Association of People with Disabilities is a convener, connector, and catalyst for change, increasing people's political and economic power with disabilities.

**Phone Number:** (800) 840-8844

**Email Address:** [communications@aapd.com](mailto:communications@aapd.com)

**Website:** <http://www.aapd.com/>

**Counties Served:** State-Wide

**Content Categories:** Financial, Legal & Advocacy

**Conditions Covered:** Anxiety, Arthritis, Allergies, Asthma, Autism Spectrum Disorder (ASD), Attention-Deficit/Hyperactivity Disorder (ADHD), Behavioral / Conduct Problem, Blindness or Problems with Seeing, Blood Disorders, Brain Injury, Concussion, or Head Injury, Cerebral Palsy (CP), Cystic Fibrosis (CF), Deafness or Problems with Hearing, Depression, Developmental Delay, Diabetes, Down Syndrome, Epilepsy / Seizure Disorder, Genetic or Inherited Condition, Heart Condition, Intellectual Disability, Learning Difficulty, Other Mental Health Condition, Speech or Language Disorder, Spina Bifida, Tourette Syndrome (TS)

# American Cleft Palate- Craniofacial Association (ACPA)



Regional Resource Guide  
of the Children and Youth with Special  
Health Care Needs (CYSHCN) Project

**Agency Name:** American Cleft Palate-Craniofacial Association (ACPA)

**Agency Description:** The American Cleft Palate-Craniofacial Association (ACPA) is a non-profit association of interested individuals and healthcare professionals who are interested in clinical care and research advancements for those affected by cleft and craniofacial conditions.

ACPA works to support the care of individuals affected by cleft and craniofacial conditions. These patients require care from a variety of specialists over time, and ACPA optimizes outcomes for individuals with oral cleft and craniofacial conditions through education, support, research and interdisciplinary team care.

**Phone Number:** (919) 933-9044

**Email Address:** [info@acpa-cpf.org](mailto:info@acpa-cpf.org)

**Website:** <http://acpa-cpf.org/>

**Counties Served:** State-Wide

**Content Categories:** Family & Supports Accessibility & Assistive Technology Information & Referral Financial, Legal & Advocacy Medical, Dental & Behavioral Health Community Living & Recreation

**Conditions Covered:** Other

# American Council of the Blind (ACB)



Regional Resource Guide  
of the Children and Youth with Special  
Health Care Needs (CYSHCN) Project

**Agency Name:** American Council of the Blind (ACB)

**Agency Description:** American Council of the Blind (ACB) advocates for equality of people who are blind and visually impaired, inspires community, and connects you with education, resources, and each other to support your independence. Find the ACB of New York here: <https://www.acb.org/affiliate-new-york>.

**Phone Number:** (800) 424-8666

**Email Address:** [info@acb.org](mailto:info@acb.org)

**Website:** <http://www.acb.org/>

**Counties Served:** State-Wide

**Content Categories:** Financial, Legal & Advocacy Information & Referral Transitioning to Adulthood (Youth)  
My Child's Condition: Disability Specific Reference Community Living & Recreation

**Conditions Covered:** Blindness or Problems with Seeing

# American Diabetes Association: Upstate New York



Regional Resource Guide  
of the Children and Youth with Special  
Health Care Needs (CYSHCN) Project

**Agency Name:** American Diabetes Association: Upstate New York

**Agency Description:** We fund research to prevent, cure and manage diabetes. We deliver services to hundreds of communities. We provide objective and credible information. We give a voice to those denied their rights because of diabetes.  
Offers literature for patient and professional education. Provides on-line and call enter support for newly diagnosed diabetes patients. Residential camp program for children living with Type 1 diabetes - camp scholarships available based on need. Eligibility: Individuals with diabetes and their families.

**Phone Number:** (800) 342-2383

**Email Address:** ADAUpstateNY@diabetes.org

**Website:** <http://www.diabetes.org/community/local-offices>

**Counties Served:** State-Wide

**Content Categories:** My Child's Condition: Disability Specific Reference Information & Referral Community Living & Recreation  
Financial, Legal & Advocacy Medical, Dental & Behavioral Health Family & Supports

**Conditions Covered:** Diabetes



# American Foundation for the Blind (AFB)



Regional Resource Guide  
of the Children and Youth with Special  
Health Care Needs (CYSHCN) Project

**Agency Name:** American Foundation for the Blind (AFB)

**Agency Description:** AFB provides the following services to the blind and visually-impaired, and to organizations/individuals working with this audience Information and referral, Publications on blindness, Data collection and information dissemination, Production of recorded materials for the blind through the Talking Books Program. We conduct a wide variety of programs to support independent living, literacy, employment and access to technology. We operate a web site which offers access to an online book store, Career Connect (employment planning tool), and Braille Bug (children's web channel for literacy).

**Phone Number:** (212) 502-7600

**Email Address:** [info@aph.org](mailto:info@aph.org)

**Website:** <http://afb.org>

**Counties Served:** State-Wide

**Content Categories:** Family & Supports Financial, Legal & Advocacy My Child's Condition: Disability Specific Reference Information & Referral

**Conditions Covered:** Blindness or Problems with Seeing

# American Lung Association



Regional Resource Guide  
of the Children and Youth with Special  
Health Care Needs (CYSHCN) Project

**Agency Name:** American Lung Association

**Agency Description:** The American Lung Association is the leading organization working to save lives by improving lung health and preventing lung disease through education, advocacy and research. The American Lung Association is also a medical Helpline, with medical professionals who help people with questions and information related to the lungs and lung disease. Our Lung HelpLine: 1-800-586-4872.

**Phone Number:** (800) 586-4872

**Email Address:** [info@lung.org](mailto:info@lung.org)

**Website:** <http://www.lung.org/lung-health-diseases/lung-disease-lookup/asthma>

**Counties Served:** State-Wide

**Content Categories:** Family & Supports Financial, Legal & Advocacy Medical, Dental & Behavioral Health Care Coordination Information & Referral My Child's Condition: Disability Specific Reference

**Conditions Covered:** Asthma

# American Medical Association: DoctorFinder



Regional Resource Guide  
of the Children and Youth with Special  
Health Care Needs (CYSHCN) Project

**Agency Name:** American Medical Association: DoctorFinder

**Agency Description:** This online physician locator helps you find a perfect match for your medical needs. DoctorFinder provides you with basic professional information on virtually every licensed physician in the United States. This includes more than 814,000 doctors.

**Phone Number:** (800) 262-3211

**Email Address:**

**Website:** <http://doctorfinder.ama-assn.org/doctorfinder/recaptcha.do>

**Counties Served:** State-Wide

**Content Categories:** Information & Referral Medical, Dental & Behavioral Health

**Conditions Covered:** Attention-Deficit/Hyperactivity Disorder (ADHD) Allergies Anxiety Arthritis Autism Spectrum Disorder (ASD) Asthma Behavioral / Conduct Problem Blood Disorders Cerebral Palsy (CP) Cystic Fibrosis (CF) Depression Developmental Delay Diabetes Down Syndrome Epilepsy / Seizure Disorder Genetic or Inherited Condition Brain Injury, Concussion, or Head Injury Deafness or Problems with Hearing Heart Condition Intellectual Disability Migraines Other Mental Health Condition Speech or Language Disorder Spina Bifida Substance Use Disorder Tourette Syndrome (TS) Blindness or Problems with Seeing Other Learning Difficulty

# Anderson Center for Autism



Regional Resource Guide  
of the Children and Youth with Special  
Health Care Needs (CYSHCN) Project

**Agency Name:** Anderson Center for Autism

**Agency Description:** Anderson Center provides education, support and outreach services, and information aimed at delivering assistance and increasing overall autism awareness. Based on the principles of Applied Behavior Analysis (ABA), our treatment approach focuses on techniques and interventions that use reinforcement to teach our individuals the skills they need to strive for independence and reach their full potential. Family Support Services offers short-term, in-home, or community services and training to families of children and adults with autism or related developmental disabilities.

**Phone Number:** (845) 889-9127

**Email Address:** [admissions@andersoncares.org](mailto:admissions@andersoncares.org).

**Website:** <http://www.andersoncenterforautism.org/>

**Counties Served:** State-Wide

**Content Categories:** Accessibility & Assistive Technology Care Coordination Community Living & Recreation Early Childhood & School Aged Family & Supports Financial, Legal & Advocacy Information & Referral Medical, Dental & Behavioral Health Transitioning to Adulthood (Youth) My Child's Condition: Disability Specific Reference

**Conditions Covered:** Autism Spectrum Disorder (ASD)

# Arthritis Foundation



Regional Resource Guide  
of the Children and Youth with Special  
Health Care Needs (CYSHCN) Project

**Agency Name:** Arthritis Foundation

**Agency Description:** The Arthritis Foundation provides resources, science, advocacy and community connections for children and youth with Juvenile idiopathic arthritis and other pediatric rheumatic diseases. Whether it's online or in person, we are all working together to promote life-changing resources and research, to push for change and to create community connections that welcome, inform and uplift.

**Phone Number:** (800) 283-7800

**Email Address:** NYC@arthritis.org

**Website:** <http://www.arthritis.org/local-offices/ny>

**Counties Served:** State-Wide

**Content Categories:** Medical, Dental & Behavioral Health | My Child's Condition: Disability Specific Reference | Early Childhood & School Aged | Community Living & Recreation | Transitioning to Adulthood (Youth) | Financial, Legal & Advocacy | Family & Supports | Information & Referral

**Conditions Covered:** Arthritis

# Assistance Dogs International, Inc. (ADI)



Regional Resource Guide  
of the Children and Youth with Special  
Health Care Needs (CYSHCN) Project

**Agency Name:** Assistance Dogs International, Inc. (ADI)

**Agency Description:** Assistance Dogs International, Inc. (ADI) is a worldwide coalition of not-for-profit programs that train and place Assistance Dogs.

**Phone Number:**

**Email Address:** [info@assistancedogsinternational.org](mailto:info@assistancedogsinternational.org)

**Website:** <http://assistancedogsinternational.org>

**Counties Served:** State-Wide

**Content Categories:** Accessibility & Assistive Technology Community Living & Recreation Transitioning to Adulthood (Youth) Family & Supports

**Conditions Covered:** Anxiety Attention-Deficit/Hyperactivity Disorder (ADHD) Arthritis Autism Spectrum Disorder (ASD) Behavioral / Conduct Problem Cerebral Palsy (CP) Cystic Fibrosis (CF) Depression Developmental Delay Down Syndrome Epilepsy / Seizure Disorder Genetic or Inherited Condition Brain Injury, Concussion, or Head Injury Deafness or Problems with Hearing Heart Condition Intellectual Disability Other Mental Health Condition Speech or Language Disorder Spina Bifida Tourette Syndrome (TS) Blindness or Problems with Seeing

# Asthma and Allergy Foundation of America (AAFA)



Regional Resource Guide  
of the Children and Youth with Special  
Health Care Needs (CYSHCN) Project

**Agency Name:** Asthma and Allergy Foundation of America (AAFA)

**Agency Description:** The Asthma and Allergy Foundation of America (AAFA), a not-for-profit organization founded in 1953, is the leading patient organization for people with asthma and allergies, and the oldest asthma and allergy patient group in the world. AAFA offers many educational programs and tools, works with the government to create laws that improve and protect quality of life and, awards research grants for the study of asthma and allergies.

**Phone Number:** (800) 727-8462

**Email Address:** [info@aafa.org](mailto:info@aafa.org)

**Website:** <http://www.aafa.org/aafa-affiliated-asthma-allergy-support-groups/>

## Counties Served:

Warren County   Saratoga County   Washington County   Nassau County   Queens County (Queens - NYC)  
Bronx County (The Bronx - NYC)   Kings County (Brooklyn - NYC)   New York County (Manhattan - NYC)  
Richmond County (Staten Island - NYC)

## Content Categories:

Family & Supports   Information & Referral   Financial, Legal & Advocacy   Early Childhood & School Aged  
Community Living & Recreation

## Conditions Covered:

Asthma   Allergies

# Autism Speaks New York State



Regional Resource Guide  
of the Children and Youth with Special  
Health Care Needs (CYSHCN) Project

**Agency Name:** Autism Speaks New York State

**Agency Description:** Autism Speaks is dedicated to promoting solutions, across the spectrum and throughout the life span, for the needs of individuals with autism and their families. We do this through advocacy and support, increasing understanding and acceptance of people with autism.

**Phone Number:** (888) 288-4762

**Email Address:** [help@autismspeaks.org](mailto:help@autismspeaks.org)

**Website:** <http://www.autismspeaks.org/new-york-state>

**Counties Served:** State-Wide

**Content Categories:** Family & Supports Community Living & Recreation My Child's Condition: Disability Specific Reference  
Financial, Legal & Advocacy

**Conditions Covered:** Autism Spectrum Disorder (ASD)



# Best Buddies



Regional Resource Guide  
of the Children and Youth with Special  
Health Care Needs (CYSHCN) Project

**Agency Name:** Best Buddies

**Agency Description:** Best Buddies International is a nonprofit organization dedicated to establishing a global volunteer movement that creates opportunities for one-to-one friendships, integrated employment, leadership development, and inclusive living for individuals with intellectual and developmental disabilities (IDD). The IDD community that Best Buddies serves includes, but is not limited to, people with Down syndrome, autism, Fragile X, Williams syndrome, cerebral palsy, traumatic brain injury and other undiagnosed disabilities.

**Phone Number:** (800) 892-8339

**Email Address:** [newyork@bestbuddies.org](mailto:newyork@bestbuddies.org)

**Website:** <http://www.bestbuddies.org/newyork/>

**Counties Served:** State-Wide

**Content Categories:** Community Living & Recreation Family & Supports Transitioning to Adulthood (Youth)

**Conditions Covered:** Autism Spectrum Disorder (ASD) Cerebral Palsy (CP) Down Syndrome Intellectual Disability Developmental Delay Cystic Fibrosis (CF) Genetic or Inherited Condition Spina Bifida Tourette Syndrome (TS) Brain Injury, Concussion, or Head Injury

# Big Brothers Big Sisters of America



Regional Resource Guide  
of the Children and Youth with Special  
Health Care Needs (CYSHCN) Project

**Agency Name:** Big Brothers Big Sisters of America

**Agency Description:** Big Brothers Big Sisters operates under the belief that inherent in every child is incredible potential. As the nation's largest donor- and volunteer-supported mentoring network, Big Brothers Big Sisters makes meaningful, monitored matches between adult volunteers ("Bigs") and children ("Littles"), ages 5 through young adulthood in communities across the country. We develop positive relationships that have a direct and lasting effect on the lives of young people.

**Phone Number:** (813) 720-8778

**Email Address:** <http://www.bbbs.org/get-involved/>

**Website:** <http://www.bbbs.org/about-us/local-offices/>

**Counties Served:** State-Wide

**Content Categories:** Family & Supports Community Living & Recreation Early Childhood & School Aged Transitioning to Adulthood (Youth)

**Conditions Covered:** Other Attention-Deficit/Hyperactivity Disorder (ADHD) Allergies Anxiety Arthritis Asthma Autism Spectrum Disorder (ASD) Behavioral / Conduct Problem Blood Disorders Cerebral Palsy (CP) Cystic Fibrosis (CF) Depression Developmental Delay Diabetes Down Syndrome Epilepsy / Seizure Disorder Genetic or Inherited Condition Brain Injury, Concussion, or Head Injury Deafness or Problems with Hearing Heart Condition Intellectual Disability Learning Difficulty Migraines Other Mental Health Condition Speech or Language Disorder Spina Bifida Substance Use Disorder Tourette Syndrome (TS)

# Board of Cooperative Educational Services (BOCES) of New York State



Regional Resource Guide  
of the Children and Youth with Special  
Health Care Needs (CYSHCN) Project

**Agency Name:** Board of Cooperative Educational Services (BOCES) of New York State

**Agency Description:** The New York State legislature created Boards of Cooperative Educational Services (BOCES) to provide shared educational programs and services to school districts within the state. Today there are 37 BOCES that are partnering with nearly all of the state's school districts to help meet students' evolving educational needs through cost-effective and relevant programs. Many BOCES programs are instructional and include, but are not limited to, services for students with disabilities.

**Phone Number:** (518) 464-3963

**Email Address:** bocesofofnys@neric.org

**Website:** <http://www.boces.org/contact-a-boces/>

## Counties Served:

Albany County Allegany County Broome County Cattaraugus County Cayuga County Chautauqua County  
Chemung County Chenango County Clinton County Columbia County Cortland County Delaware County  
Dutchess County Erie County Essex County Franklin County Fulton County Genesee County Greene County

## Content Categories:

Care Coordination Family & Supports Early Childhood & School Aged Financial, Legal & Advocacy  
Information & Referral Transitioning to Adulthood (Youth)

## Conditions Covered:

Attention-Deficit/Hyperactivity Disorder (ADHD) Allergies Anxiety Arthritis Asthma Autism Spectrum Disorder (ASD)  
Behavioral / Conduct Problem Blood Disorders Cerebral Palsy (CP) Cystic Fibrosis (CF) Depression  
Developmental Delay Diabetes Down Syndrome Epilepsy / Seizure Disorder Genetic or Inherited Condition  
Brain Injury, Concussion, or Head Injury Deafness or Problems with Hearing Heart Condition Intellectual Disability  
Learning Difficulty Migraines Other Other Mental Health Condition Speech or Language Disorder Spina Bifida  
Substance Use Disorder Tourette Syndrome (TS) Blindness or Problems with Seeing

# Brain Injury Association of New York State (BIANYS)



Regional Resource Guide  
of the Children and Youth with Special  
Health Care Needs (CYSHCN) Project

**Agency Name:** Brain Injury Association of New York State (BIANYS)

**Agency Description:** Brain Injury Association of New York State (BIANYS) is a statewide non-profit membership organization that advocates on behalf of individuals with brain injuries and their families. BIANYS provides education, advocacy, and community support services that lead to improved outcomes for children and adults with brain injuries and their families. The Association also offers a toll free family helpline, chapters and support groups throughout the state, prevention programs, professional development programs, and a video and publications library. BIANYS plays a central role in the development of public policy on the federal, state and local level.

**Phone Number:** (800)-444-6443

**Email Address:** [info@bianys.org](mailto:info@bianys.org)

**Website:** <http://bianys.org/>

**Counties Served:** State-Wide

**Content Categories:** My Child's Condition: Disability Specific Reference Family & Supports Financial, Legal & Advocacy  
Community Living & Recreation Early Childhood & School Aged Transitioning to Adulthood (Youth)

**Conditions Covered:** Brain Injury, Concussion, or Head Injury

# Care Design New York



Regional Resource Guide  
of the Children and Youth with Special  
Health Care Needs (CYSHCN) Project

**Agency Name:** Care Design New York

**Agency Description:** Care Design New York (NY) was created with the involvement and participation of over 70 agencies with long and successful histories of specializing in the provision of services to children and adults with Intellectual and/or Developmental Disabilities (I/DD). Our story is rooted specifically in the provision of Medicaid Service Coordination. Our mission is to assist individuals with I/DD to get the supports and services they need to live a quality life.

**Phone Number:** (518) 235-1888

**Email Address:** [memberfeedback@caresignny.org](mailto:memberfeedback@caresignny.org)

**Website:** <http://caresignny.org/>

## Counties Served:

Albany County   Bronx County (The Bronx - NYC)   Clinton County   Columbia County   Dutchess County   Essex County  
Franklin County   Fulton County   Hamilton County   Greene County   Kings County (Brooklyn - NYC)  
Montgomery County   Nassau County   New York County (Manhattan - NYC)   Orange County   Putnam County

## Content Categories:

Care Coordination   Family & Supports   Government Agency   Information & Referral   Transitioning to Adulthood (Youth)  
Early Childhood & School Aged

## Conditions Covered:

Allergies   Anxiety   Arthritis   Asthma   Attention-Deficit/Hyperactivity Disorder (ADHD)   Autism Spectrum Disorder (ASD)  
Behavioral / Conduct Problem   Blood Disorders   Brain Injury, Concussion, or Head Injury   Cerebral Palsy (CP)  
Cystic Fibrosis (CF)   Depression   Developmental Delay   Diabetes   Down Syndrome   Epilepsy / Seizure Disorder  
Genetic or Inherited Condition   Deafness or Problems with Hearing   Heart Condition   Intellectual Disability  
Learning Difficulty   Migraines   Other Mental Health Condition   Speech or Language Disorder   Spina Bifida  
Substance Use Disorder   Tourette Syndrome (TS)   Blindness or Problems with Seeing   Other

# Caregiver Action Network (CAN)



Regional Resource Guide  
of the Children and Youth with Special  
Health Care Needs (CYSHCN) Project

**Agency Name:** Caregiver Action Network (CAN)

**Agency Description:** Caregiver Action Network (CAN) is the nation's leading family caregiver organization working to improve the quality of life for Americans who care for loved ones with chronic conditions, disabilities, disease, or the frailties of old age. CAN serves a broad spectrum of family caregivers ranging from the parents of children with significant health needs to the families and friends of wounded soldiers, from a young couple dealing with a diagnosis of MS to adult children caring for parents with Alzheimer's disease.

**Phone Number:** (202) 454-3970

**Email Address:** [info@caregiveraction.org](mailto:info@caregiveraction.org)

**Website:** <http://caregiveraction.org>

**Counties Served:** State-Wide

**Content Categories:** Accessibility & Assistive Technology, Care Coordination, Community Living & Recreation, Financial, Legal & Advocacy, Information & Referral, Medical, Dental & Behavioral Health, Transitioning to Adulthood (Youth), Family & Supports, Early Childhood & School Aged

**Conditions Covered:** Attention-Deficit/Hyperactivity Disorder (ADHD), Allergies, Anxiety, Arthritis, Autism Spectrum Disorder (ASD), Asthma, Behavioral / Conduct Problem, Blood Disorders, Cerebral Palsy (CP), Cystic Fibrosis (CF), Depression, Developmental Delay, Diabetes, Down Syndrome, Epilepsy / Seizure Disorder, Genetic or Inherited Condition, Brain Injury, Concussion, or Head Injury, Deafness or Problems with Hearing, Heart Condition, Intellectual Disability, Migraines, Other Mental Health Condition, Speech or Language Disorder, Spina Bifida, Substance Use Disorder, Tourette Syndrome (TS), Blindness or Problems with Seeing, Other, Learning Difficulty

# Catholic Charities USA



Regional Resource Guide  
of the Children and Youth with Special  
Health Care Needs (CYSHCN) Project

**Agency Name:** Catholic Charities USA

**Agency Description:** The mission of Catholic Charities is to provide service to people in need, to advocate for justice in social structures, and to call the entire church and other people of good will to do the same.

**Phone Number:** (703) 549-1390

**Email Address:**

**Website:** <http://www.catholiccharitiesusa.org/find-help/>

**Counties Served:** State-Wide

**Content Categories:** Community Living & Recreation Family & Supports Financial, Legal & Advocacy Information & Referral

**Conditions Covered:** Allergies Anxiety Arthritis Asthma Attention-Deficit/Hyperactivity Disorder (ADHD) Autism Spectrum Disorder (ASD) Behavioral / Conduct Problem Blood Disorders Brain Injury, Concussion, or Head Injury Cerebral Palsy (CP) Cystic Fibrosis (CF) Depression Developmental Delay Diabetes Down Syndrome Epilepsy / Seizure Disorder Genetic or Inherited Condition Deafness or Problems with Hearing Heart Condition Intellectual Disability Learning Difficulty Migraines Other Other Mental Health Condition Speech or Language Disorder Spina Bifida Substance Use Disorder Tourette Syndrome (TS) Blindness or Problems with Seeing

# Center for Disability Services (CFDSNY)



Regional Resource Guide  
of the Children and Youth with Special  
Health Care Needs (CYSHCN) Project

**Agency Name:** Center for Disability Services (CFDSNY)

**Agency Description:** The Center for Disability Services annually provides programs and services to over 12,000 individuals, ranging from infants to senior citizens, and their families. We provide services for over 300 different diagnoses of disabilities included Cerebral Palsy, Developmental Disabilities, Multiple Sclerosis, Autism Spectrum Disorders, Epilepsy, Spina Bifida, TBI and Down syndrome. Our services range from intensive medical care to residential services, to dental care to mental health.

**Phone Number:** (518) 437-5700

**Email Address:**

**Website:** <http://www.cfdsny.org/>

**Counties Served:**

Albany County Schenectady County Rensselaer County Fulton County Montgomery County Columbia County  
Schoharie County Saratoga County Warren County Washington County

**Content Categories:**

Accessibility & Assistive Technology Care Coordination Community Living & Recreation Early Childhood & School Aged  
Family & Supports Financial, Legal & Advocacy Information & Referral Medical, Dental & Behavioral Health  
Transitioning to Adulthood (Youth)

**Conditions Covered:**

Allergies Anxiety Asthma Blood Disorders Cerebral Palsy (CP) Cystic Fibrosis (CF) Depression  
Developmental Delay Diabetes Down Syndrome Genetic or Inherited Condition Brain Injury, Concussion, or Head Injury  
Deafness or Problems with Hearing Heart Condition Intellectual Disability Learning Difficulty Migraines  
Other Mental Health Condition Speech or Language Disorder Spina Bifida Substance Use Disorder  
Tourette Syndrome (TS) Blindness or Problems with Seeing Other Attention-Deficit/Hyperactivity Disorder (ADHD)  
Arthritis Autism Spectrum Disorder (ASD) Behavioral / Conduct Problem Epilepsy / Seizure Disorder



# Center for Parent Information and Resources (CPIR)



Regional Resource Guide  
of the Children and Youth with Special  
Health Care Needs (CYSHCN) Project

**Agency Name:** Center for Parent Information and Resources (CPIR)

**Agency Description:** The Center for Parent Information and Resources (CPIR) serves as a central resource of information for parents, individuals, caregivers and other people involved in the lives of people with special needs. You can find Parents Centers in New York here: <https://www.parentcenterhub.org/find-your-center/>.

**Phone Number:** (973) 642-8100

**Email Address:**

**Website:** <http://www.parentcenterhub.org/>

**Counties Served:** State-Wide

**Content Categories:** Information & Referral, Transitioning to Adulthood (Youth), Family & Supports, Early Childhood & School Aged

**Conditions Covered:** Attention-Deficit/Hyperactivity Disorder (ADHD), Allergies, Anxiety, Arthritis, Autism Spectrum Disorder (ASD), Asthma, Behavioral / Conduct Problem, Blood Disorders, Cerebral Palsy (CP), Cystic Fibrosis (CF), Depression, Developmental Delay, Diabetes, Down Syndrome, Epilepsy / Seizure Disorder, Genetic or Inherited Condition, Brain Injury, Concussion, or Head Injury, Deafness or Problems with Hearing, Heart Condition, Intellectual Disability, Migraines, Other Mental Health Condition, Speech or Language Disorder, Spina Bifida, Substance Use Disorder, Tourette Syndrome (TS), Blindness or Problems with Seeing, Other, Learning Difficulty

# Cerebral Palsy Association of New York State



Regional Resource Guide  
of the Children and Youth with Special  
Health Care Needs (CYSHCN) Project

**Agency Name:** Cerebral Palsy Association of New York State

**Agency Description:** The mission of Cerebral Palsy Associations of New York State is to provide for the exchange of ideas, education and communication between groups and people interested in advocacy for people with cerebral palsy and other developmental disabilities, as well as people with significant other disabilities for which the Corporation's local Affiliates provide support.

**Phone Number:** (518) 235-1880

**Email Address:** [info@cpstate.org](mailto:info@cpstate.org)

**Website:** <http://www.cpstate.org/affiliates/>

**Counties Served:** State-Wide

**Content Categories:** Community Living & Recreation Family & Supports Financial, Legal & Advocacy Information & Referral  
My Child's Condition: Disability Specific Reference

**Conditions Covered:** Cerebral Palsy (CP) Developmental Delay

# Chai Lifeline



Regional Resource Guide  
of the Children and Youth with Special  
Health Care Needs (CYSHCN) Project

**Agency Name:** Chai Lifeline

**Agency Description:** Chai Lifeline's programs and services meet the unique emotional, social and financial needs of families living with serious illness or loss. From the moment of diagnosis or trauma, Chai Lifeline's professionals and trained, compassionate volunteers step in to help restore equilibrium and bring joy and hope back into lives devastated by illness and crises. Offers respite, tutoring, camps, and transportation.

**Phone Number:** (212) 465-1300

**Email Address:** [info@chailifeline.org](mailto:info@chailifeline.org)

**Website:** <http://chailifeline.org>

**Counties Served:** State-Wide

**Content Categories:** Community Living & Recreation Medical, Dental & Behavioral Health Family & Supports  
Accessibility & Assistive Technology

**Conditions Covered:** Genetic or Inherited Condition Blood Disorders Other Brain Injury, Concussion, or Head Injury Cystic Fibrosis (CF)  
Spina Bifida Arthritis Diabetes Cerebral Palsy (CP) Epilepsy / Seizure Disorder Deafness or Problems with Hearing  
Heart Condition Asthma Allergies Attention-Deficit/Hyperactivity Disorder (ADHD) Blindness or Problems with Seeing  
Tourette Syndrome (TS) Behavioral / Conduct Problem Anxiety Autism Spectrum Disorder (ASD) Depression  
Developmental Delay Down Syndrome Intellectual Disability Learning Difficulty Other Mental Health Condition  
Migraines Speech or Language Disorder Substance Use Disorder

# CHARGE Syndrome Foundation



Regional Resource Guide  
of the Children and Youth with Special  
Health Care Needs (CYSHCN) Project

**Agency Name:** CHARGE Syndrome Foundation

**Agency Description:** The CHARGE Syndrome Foundation leads and partners to improve the lives of people with CHARGE syndrome locally, nationally, and internationally through outreach, education, and research. The primary goals of the Foundation include: growing our outreach and support programs; increasing our knowledge base; promoting awareness; building networks and partnerships; and investing in leading-edge research.

**Phone Number:** (800) 442-7604

**Email Address:** [info@chargesyndrome.org](mailto:info@chargesyndrome.org)

**Website:** <http://www.chargesyndrome.org/>

**Counties Served:** State-Wide

**Content Categories:** Family & Supports Information & Referral My Child's Condition: Disability Specific Reference Financial, Legal & Advocacy

**Conditions Covered:** Genetic or Inherited Condition

**Agency Name:** Child Mind Institute

**Agency Description:** The Child Mind Institute is an independent, national nonprofit dedicated to transforming the lives of children and families struggling with mental health and learning disorders. Our teams work every day to deliver the highest standards of care, advance the science of the developing brain and empower parents, professionals and policymakers to support children when and where they need it most.

**Phone Number:** (212) 308-3118

**Email Address:** [developmentInfo@childmind.org](mailto:developmentInfo@childmind.org)

**Website:** <http://childmind.org/>

**Counties Served:** State-Wide

**Content Categories:** Accessibility & Assistive Technology Care Coordination Family & Supports Early Childhood & School Aged  
Financial, Legal & Advocacy Medical, Dental & Behavioral Health Transitioning to Adulthood (Youth)  
Information & Referral

**Conditions Covered:** Developmental Delay Learning Difficulty Intellectual Disability Anxiety Depression Other Mental Health Condition  
Down Syndrome Genetic or Inherited Condition Brain Injury, Concussion, or Head Injury Speech or Language Disorder  
Substance Use Disorder

# Community, Work & Independence, Inc. (CWI)



Regional Resource Guide  
of the Children and Youth with Special  
Health Care Needs (CYSHCN) Project

**Agency Name:** Community, Work & Independence, Inc. (CWI)

**Agency Description:** Community, Work & Independence, Inc. (CWI) is headquartered in Glens Falls, NY and offers a diverse array of services for individuals with disabilities in Warren, Washington, Saratoga and Essex Counties. Services include: a residential, day habilitation, community supports, pre-vocational and employment services, clinical services and a Consumer Directed Personal Assistance Program.

**Phone Number:** (518) 793-4700

**Email Address:** [info@cwinc.org](mailto:info@cwinc.org)

**Website:** <http://cwinc.org/>

**Counties Served:**

Warren County Washington County Essex County Saratoga County

**Content Categories:**

Accessibility & Assistive Technology Care Coordination Community Living & Recreation Early Childhood & School Aged Family & Supports Financial, Legal & Advocacy Information & Referral Medical, Dental & Behavioral Health Transitioning to Adulthood (Youth)

**Conditions Covered:**

Allergies Anxiety Asthma Blood Disorders Cerebral Palsy (CP) Cystic Fibrosis (CF) Depression Developmental Delay Diabetes Down Syndrome Genetic or Inherited Condition Brain Injury, Concussion, or Head Injury Deafness or Problems with Hearing Heart Condition Intellectual Disability Learning Difficulty Migraines Other Mental Health Condition Speech or Language Disorder Spina Bifida Substance Use Disorder Tourette Syndrome (TS) Blindness or Problems with Seeing Other Attention-Deficit/Hyperactivity Disorder (ADHD) Arthritis Autism Spectrum Disorder (ASD) Behavioral / Conduct Problem Epilepsy / Seizure Disorder

# Complex Child



Regional Resource Guide  
of the Children and Youth with Special  
Health Care Needs (CYSHCN) Project

**Agency Name:** Complex Child

**Agency Description:** Complex Child is a free, monthly online magazine written by parents of children with special healthcare needs and disabilities. It is intended to provide medical information, along with personal experiences, in simple language that other parents can understand.

**Phone Number:**

**Email Address:** [info@complexchild.org](mailto:info@complexchild.org)

**Website:** <http://complexchild.org/>

**Counties Served:** State-Wide

**Content Categories:** Family & Supports Accessibility & Assistive Technology Information & Referral

**Conditions Covered:** Attention-Deficit/Hyperactivity Disorder (ADHD) Autism Spectrum Disorder (ASD) Behavioral / Conduct Problem Blood Disorders Brain Injury, Concussion, or Head Injury Cerebral Palsy (CP) Cystic Fibrosis (CF) Developmental Delay Epilepsy / Seizure Disorder Allergies Anxiety Arthritis Asthma Depression Diabetes Down Syndrome Genetic or Inherited Condition Deafness or Problems with Hearing Heart Condition Intellectual Disability Learning Difficulty Migraines Other Other Mental Health Condition Speech or Language Disorder Spina Bifida Substance Use Disorder Tourette Syndrome (TS) Blindness or Problems with Seeing

# Constructive Partnerships Unlimited



Regional Resource Guide  
of the Children and Youth with Special  
Health Care Needs (CYSHCN) Project

**Agency Name:** Constructive Partnerships Unlimited

**Agency Description:** Constructive Partnerships Unlimited (formerly Cerebral Palsy Associations of New York State) specializes in a wide range of individualized programs and support for people with intellectual and developmental disabilities. We provide residential, health care, day habilitation and other services in the five Boroughs of New York City and Hudson Valley region to persons with intellectual, developmental and physical disabilities.

**Phone Number:** (212) 947-5770

**Email Address:** CPUnlimitedInquiries@cpofnys.org

**Website:** <http://www.cpunlimited.org/>

## Counties Served:

Putnam County   Rockland County   Westchester County   Dutchess County   Sullivan County   Ulster County  
Albany County   Columbia County   Greene County   Rensselaer County   Orange County  
Bronx County (The Bronx - NYC)   Kings County (Brooklyn - NYC)   New York County (Manhattan - NYC)

## Content Categories:

Transitioning to Adulthood (Youth)   Community Living & Recreation   Medical, Dental & Behavioral Health  
Family & Supports

## Conditions Covered:

Cerebral Palsy (CP)   Brain Injury, Concussion, or Head Injury   Epilepsy / Seizure Disorder   Intellectual Disability  
Developmental Delay   Attention-Deficit/Hyperactivity Disorder (ADHD)   Autism Spectrum Disorder (ASD)  
Genetic or Inherited Condition   Learning Difficulty   Blindness or Problems with Seeing   Deafness or Problems with Hearing  
Speech or Language Disorder   Tourette Syndrome (TS)   Arthritis   Down Syndrome   Other   Spina Bifida



# Council for Exceptional Children (CEC)



Regional Resource Guide  
of the Children and Youth with Special  
Health Care Needs (CYSHCN) Project

**Agency Name:** Council for Exceptional Children (CEC)

**Agency Description:** The Council for Exceptional Children (CEC) advocates for appropriate governmental policies and is known as THE source for information, resources, and professional development for special educators. CEC has local Units in all 50 states and Canada, as well as 18 optional Special Interest Divisions focused on a specific topic, specialty area, role, or exceptionality. We also have CEC Student Chapters at hundreds of colleges and universities.

**Phone Number:** (888) 232-7733

**Email Address:** [service@cec.sped.org](mailto:service@cec.sped.org)

**Website:** <http://www.cec.sped.org>

**Counties Served:** State-Wide

**Content Categories:** Financial, Legal & Advocacy Information & Referral Transitioning to Adulthood (Youth)

**Conditions Covered:** Attention-Deficit/Hyperactivity Disorder (ADHD) Allergies Anxiety Arthritis Autism Spectrum Disorder (ASD) Asthma Behavioral / Conduct Problem Blood Disorders Cerebral Palsy (CP) Cystic Fibrosis (CF) Depression Developmental Delay Diabetes Down Syndrome Epilepsy / Seizure Disorder Genetic or Inherited Condition Brain Injury, Concussion, or Head Injury Deafness or Problems with Hearing Heart Condition Intellectual Disability Migraines Other Mental Health Condition Speech or Language Disorder Spina Bifida Substance Use Disorder Tourette Syndrome (TS) Blindness or Problems with Seeing Other Learning Difficulty

# Council of Parent Attorneys and Advocates, Inc. (COPAA)



Regional Resource Guide  
of the Children and Youth with Special  
Health Care Needs (CYSHCN) Project

**Agency Name:** Council of Parent Attorneys and Advocates, Inc. (COPAA)

**Agency Description:** The Council of Parent Attorneys and Advocates, Inc. (COPAA) is an independent, nonprofit, organization of attorneys, advocates, parents and related professionals. COPAA focuses on the rights of children who receive special education services and supports, and who are eligible to be served under the Individuals with Disabilities Education Act (IDEA) and other statutes. Parents who are looking to find a special education attorney, a special education advocate, or a related professional may look up referrals in the COPAA Member Directory.

**Phone Number:** (844) 426-7224

**Email Address:** [exec@copaa.org](mailto:exec@copaa.org)

**Website:** <http://www.copaa.org/>

**Counties Served:** State-Wide

**Content Categories:** Financial, Legal & Advocacy Information & Referral

**Conditions Covered:** Attention-Deficit/Hyperactivity Disorder (ADHD) Allergies Anxiety Arthritis Asthma Autism Spectrum Disorder (ASD) Behavioral / Conduct Problem Blood Disorders Cerebral Palsy (CP) Cystic Fibrosis (CF) Depression Developmental Delay Diabetes Down Syndrome Epilepsy / Seizure Disorder Genetic or Inherited Condition Brain Injury, Concussion, or Head Injury Deafness or Problems with Hearing Heart Condition Intellectual Disability Learning Difficulty Migraines Other Other Mental Health Condition Speech or Language Disorder Spina Bifida Substance Use Disorder Tourette Syndrome (TS) Blindness or Problems with Seeing

# Creative Adaptations For Learning (CAL)



Regional Resource Guide  
of the Children and Youth with Special  
Health Care Needs (CYSHCN) Project

**Agency Name:** Creative Adaptations For Learning (CAL)

**Agency Description:** Creative Adaptations for Learning (CAL) creates and publishes innovative educational braille flashcards, embossed pictures, and tactile illustrations that bring raised line drawings to life. CAL creates tactile graphics for children and adults who are blind, visually impaired, or have dyslexia, autism, cognitive learning disability, or other special needs.

**Phone Number:** (516) 466-9143

**Email Address:** [calinfo@cal-s.org](mailto:calinfo@cal-s.org)

**Website:** <http://www.cal-s.org>

**Counties Served:** State-Wide

**Content Categories:** My Child's Condition: Disability Specific Reference Family & Supports Accessibility & Assistive Technology  
Early Childhood & School Aged

**Conditions Covered:** Autism Spectrum Disorder (ASD) Intellectual Disability Learning Difficulty Attention-Deficit/Hyperactivity Disorder (ADHD)  
Blindness or Problems with Seeing Down Syndrome Speech or Language Disorder Genetic or Inherited Condition  
Brain Injury, Concussion, or Head Injury Cerebral Palsy (CP) Developmental Delay

# Cystic Fibrosis (CF) Foundation



Regional Resource Guide  
of the Children and Youth with Special  
Health Care Needs (CYSHCN) Project

**Agency Name:** Cystic Fibrosis (CF) Foundation

**Agency Description:** The mission of the Cystic Fibrosis Foundation is to cure cystic fibrosis and to provide all people with CF the opportunity to lead long, fulfilling lives by funding research and drug development, partnering with the CF community, and advancing high-quality specialized care. There are multiple local CF chapters across New York State.

**Phone Number:** (800) 344-4823

**Email Address:** [info@cff.org](mailto:info@cff.org)

**Website:** <http://www.cff.org/Locations/Find-a-Local-Chapter/>

**Counties Served:** State-Wide

**Content Categories:** Family & Supports Information & Referral Community Living & Recreation Financial, Legal & Advocacy Medical, Dental & Behavioral Health My Child's Condition: Disability Specific Reference Care Coordination

**Conditions Covered:** Cystic Fibrosis (CF)

# Depression and Bipolar Support Alliance (DBSA)



Regional Resource Guide  
of the Children and Youth with Special  
Health Care Needs (CYSHCN) Project

**Agency Name:** Depression and Bipolar Support Alliance (DBSA)

**Agency Description:** The Depression and Bipolar Support Alliance (DBSA) envisions wellness for people living with mood disorders (depression and bipolar disorder). DBSA provides hope, help, support, and education to improve the lives of people who have mood disorders.

**Phone Number:** (800) 826-3632

**Email Address:**

**Website:** <http://www.dbsalliance.org/support/chapters-and-support-groups/find-a->

**Counties Served:**

Westchester County   Rockland County   Nassau County   New York County (Manhattan - NYC)   Albany County  
Suffolk County

**Content**

**Categories:**

Family & Supports   Community Living & Recreation   Transitioning to Adulthood (Youth)  
My Child's Condition: Disability Specific Reference   Financial, Legal & Advocacy   Information & Referral  
Medical, Dental & Behavioral Health

**Conditions Covered:**

Anxiety   Depression   Other Mental Health Condition

# Described and Captioned Media Program (DCMP)



Regional Resource Guide  
of the Children and Youth with Special  
Health Care Needs (CYSHCN) Project

**Agency Name:** Described and Captioned Media Program (DCMP)

**Agency Description:** We're here to educate students with sensory disabilities, along with their parents and teachers. Our educational content is carefully customized to serve the needs of K-12 students, as well as adult students studying to meet the needs of blind and deaf students. DCMP has thousands of videos that are accessible and there are no charges for membership or any of DCMP's services.

**Phone Number:** (800) 237-6213

**Email Address:**

**Website:** <http://dcmp.org/>

**Counties Served:** State-Wide

**Content Categories:** Information & Referral Early Childhood & School Aged Accessibility & Assistive Technology Transitioning to Adulthood (Youth)

**Conditions Covered:** Blindness or Problems with Seeing Deafness or Problems with Hearing

# Disability and Sexuality Access Network (DASANetwork)



Regional Resource Guide  
of the Children and Youth with Special  
Health Care Needs (CYSHCN) Project

**Agency Name:** Disability and Sexuality Access Network (DASANetwork)

**Agency Description:** The Disability and Sexuality Access Network (DASANetwork) is a community of disabled peers, researchers, practitioners, activists, allies, students, artists, and others who believe that access to sexuality, pleasure, and intimacy is a fundamental human right.

**Phone Number:**

**Email Address:** [info@dasanetwork.org](mailto:info@dasanetwork.org)

**Website:** <http://dasanetwork.org/>

**Counties Served:** State-Wide

**Content Categories:** Financial, Legal & Advocacy Information & Referral

**Conditions Covered:** Allergies Anxiety Arthritis Asthma Attention-Deficit/Hyperactivity Disorder (ADHD) Autism Spectrum Disorder (ASD) Behavioral / Conduct Problem Blood Disorders Brain Injury, Concussion, or Head Injury Cerebral Palsy (CP) Cystic Fibrosis (CF) Depression Developmental Delay Diabetes Down Syndrome Epilepsy / Seizure Disorder Genetic or Inherited Condition Deafness or Problems with Hearing Heart Condition Intellectual Disability Learning Difficulty Migraines Other Other Mental Health Condition Speech or Language Disorder Spina Bifida Substance Use Disorder Tourette Syndrome (TS) Blindness or Problems with Seeing

# Disability Horizons



Regional Resource Guide  
of the Children and Youth with Special  
Health Care Needs (CYSHCN) Project

**Agency Name:** Disability Horizons

**Agency Description:** Disability Horizons magazine is an online, disability lifestyle publication that aims to give disabled people a voice. Disability Horizons publishes articles on a wide variety of topics, all to support the aim of a world where disabled people live exactly as they choose to. You can sign up for our newsletter to get all our articles directly to your inbox, along with our Ultimate Disability Survival guide.

**Phone Number:**

**Email Address:** [martyn@disabilityhorizons.com](mailto:martyn@disabilityhorizons.com)

**Website:** <http://disabilityhorizons.com>

**Counties Served:** State-Wide

**Content Categories:** Accessibility & Assistive Technology, Community Living & Recreation, Financial, Legal & Advocacy, Information & Referral, Transitioning to Adulthood (Youth), Family & Supports

**Conditions Covered:** Attention-Deficit/Hyperactivity Disorder (ADHD), Allergies, Anxiety, Arthritis, Autism Spectrum Disorder (ASD), Asthma, Behavioral / Conduct Problem, Blood Disorders, Cerebral Palsy (CP), Cystic Fibrosis (CF), Depression, Developmental Delay, Diabetes, Down Syndrome, Epilepsy / Seizure Disorder, Genetic or Inherited Condition, Brain Injury, Concussion, or Head Injury, Deafness or Problems with Hearing, Heart Condition, Intellectual Disability, Migraines, Other Mental Health Condition, Speech or Language Disorder, Spina Bifida, Substance Use Disorder, Tourette Syndrome (TS), Blindness or Problems with Seeing, Other, Learning Difficulty



# Disability Rights New York (DRNY)



Regional Resource Guide  
of the Children and Youth with Special  
Health Care Needs (CYSHCN) Project

**Agency Name:** Disability Rights New York (DRNY)

**Agency Description:** DRNY advocates for the civil and legal rights for New Yorkers with disabilities. DRNY provides free legal and advocacy services to individuals with disabilities. Working tirelessly to protect and advance the rights of children and adults with disabilities, DRNY is committed to enabling those we serve to exercise their own life choices and fully participate in community life.

**Phone Number:** (518) 432-7861

**Email Address:** mail@DRNY.org

**Website:** <http://www.drny.org/>

**Counties Served:** State-Wide

**Content Categories:** Family & Supports, Financial, Legal & Advocacy, Information & Referral, Community Living & Recreation

**Conditions Covered:** Brain Injury, Concussion, or Head Injury, Developmental Delay, Down Syndrome, Intellectual Disability, Learning Difficulty, Other Mental Health Condition, Cerebral Palsy (CP), Allergies, Anxiety, Arthritis, Asthma, Attention-Deficit/Hyperactivity Disorder (ADHD), Autism Spectrum Disorder (ASD), Behavioral / Conduct Problem, Blood Disorders, Cystic Fibrosis (CF), Depression, Diabetes, Epilepsy / Seizure Disorder, Genetic or Inherited Condition, Deafness or Problems with Hearing, Heart Condition, Migraines, Other, Speech or Language Disorder, Spina Bifida, Substance Use Disorder, Tourette Syndrome (TS), Blindness or Problems with Seeing

# Ditch the Label



Regional Resource Guide  
of the Children and Youth with Special  
Health Care Needs (CYSHCN) Project

**Agency Name:** Ditch the Label

**Agency Description:** Ditch the Label is a leading global youth charity helping young people aged 12-25 through some of the issues affecting them the most. Bullying, mental health, relationships, identity – whatever the issue, were there.

**Phone Number:** (818) 963-5870

**Email Address:** Hello@DitchtheLabel.org

**Website:** <http://www.ditchthelabel.org/>

**Counties Served:** State-Wide

**Content Categories:** Family & Supports Information & Referral Community Living & Recreation Medical, Dental & Behavioral Health  
Transitioning to Adulthood (Youth) Financial, Legal & Advocacy

**Conditions Covered:** Anxiety Depression Other Mental Health Condition Substance Use Disorder

# Easterseals New York



Regional Resource Guide  
of the Children and Youth with Special  
Health Care Needs (CYSHCN) Project

**Agency Name:** Easterseals New York

**Agency Description:** Easterseals provides exceptional services, education, outreach, and advocacy so that people living with autism and other disabilities can live, learn, work and play in our communities. From child development centers to physical rehabilitation and job training for people with disabilities, Easterseals offers a variety of services to help people with disabilities.

**Phone Number:** (212) 943-4364

**Email Address:**

**Website:** <http://www.easterseals.com/newyork/connect-locally/new-york.html>

## Counties Served:

Westchester County   Suffolk County   Sullivan County   Delaware County   Ulster County   Greene County  
Orange County   Albany County   Monroe County   New York County (Manhattan - NYC)   Bronx County (The Bronx - NYC)  
Queens County (Queens - NYC)   Kings County (Brooklyn - NYC)

## Content Categories:

Family & Supports   Community Living & Recreation   Information & Referral   Early Childhood & School Aged  
Financial, Legal & Advocacy   Transitioning to Adulthood (Youth)   Medical, Dental & Behavioral Health

## Conditions Covered:

Attention-Deficit/Hyperactivity Disorder (ADHD)   Autism Spectrum Disorder (ASD)   Developmental Delay  
Intellectual Disability   Learning Difficulty   Allergies   Anxiety   Arthritis   Asthma   Behavioral / Conduct Problem  
Blood Disorders   Brain Injury, Concussion, or Head Injury   Cerebral Palsy (CP)   Cystic Fibrosis (CF)   Depression   Diabetes  
Down Syndrome   Epilepsy / Seizure Disorder   Genetic or Inherited Condition   Deafness or Problems with Hearing  
Heart Condition   Migraines   Other   Other Mental Health Condition   Speech or Language Disorder   Spina Bifida  
Substance Use Disorder   Tourette Syndrome (TS)   Blindness or Problems with Seeing

# Emotions Anonymous International (EAI)



Regional Resource Guide  
of the Children and Youth with Special  
Health Care Needs (CYSHCN) Project

**Agency Name:** Emotions Anonymous International (EAI)

**Agency Description:** Emotions Anonymous International (EAI) is a nonprofit organization that facilitates the ongoing efforts of an international fellowship of men and women who desire to improve their emotional well-being. EA members come together in weekly meetings for the purpose of working toward recovery from any sort of emotional difficulties.

**Phone Number:** (651) 647-9712

**Email Address:** [info@emotionsanonymous.org](mailto:info@emotionsanonymous.org)

**Website:** <http://emotionsanonymous.org/>

**Counties Served:** State-Wide

**Content Categories:** Family & Supports, Transitioning to Adulthood (Youth), Community Living & Recreation, Information & Referral, Medical, Dental & Behavioral Health

**Conditions Covered:** Depression, Anxiety, Other Mental Health Condition, Substance Use Disorder

# endABUSE of People with Disabilities



Regional Resource Guide  
of the Children and Youth with Special  
Health Care Needs (CYSHCN) Project

**Agency Name:** endABUSE of People with Disabilities

**Agency Description:** endAbuse of People with Disabilities is a website that provides a repository of accurate and reliable resources about the abuse of people with disabilities. Users can access multi-media content that offers information about the forms of abuse, targets of abuse, peer-to-peer support, and advocacy. Additionally, those in need have the ability to get immediate assistance from the "Get Help Now" section which includes a "quick escape" browsing option.

**Phone Number:** (855) 274-8222

**Email Address:** cvs@vera.org

**Website:** <http://www.endabusepwd.org/>

**Counties Served:** State-Wide

**Content Categories:** Accessibility & Assistive Technology, Care Coordination, Community Living & Recreation, Financial, Legal & Advocacy, Information & Referral, Medical, Dental & Behavioral Health, Transitioning to Adulthood (Youth), Family & Supports, Early Childhood & School Aged

**Conditions Covered:** Attention-Deficit/Hyperactivity Disorder (ADHD), Allergies, Anxiety, Arthritis, Autism Spectrum Disorder (ASD), Asthma, Behavioral / Conduct Problem, Blood Disorders, Cerebral Palsy (CP), Cystic Fibrosis (CF), Depression, Developmental Delay, Diabetes, Down Syndrome, Epilepsy / Seizure Disorder, Genetic or Inherited Condition, Brain Injury, Concussion, or Head Injury, Deafness or Problems with Hearing, Heart Condition, Intellectual Disability, Migraines, Other Mental Health Condition, Speech or Language Disorder, Spina Bifida, Substance Use Disorder, Tourette Syndrome (TS), Blindness or Problems with Seeing, Other, Learning Difficulty

# Epilepsy Foundation



Regional Resource Guide  
of the Children and Youth with Special  
Health Care Needs (CYSHCN) Project

**Agency Name:** Epilepsy Foundation

**Agency Description:** The Epilepsy Foundation increases awareness and changes the conversation around epilepsy, improves and saves lives through care, advocacy, research and new therapies, and education, and mobilizes everyone to take action. There are multiple local Epilepsy Foundations in New York.

**Phone Number:** (800) 332-1000

**Email Address:** [ContactUs@efa.org](mailto:ContactUs@efa.org)

**Website:** <http://www.epilepsy.com/affiliates?>

**Counties Served:**

- Bronx County (The Bronx - NYC)
- Kings County (Brooklyn - NYC)
- New York County (Manhattan - NYC)
- Queens County (Queens - NYC)
- Richmond County (Staten Island - NYC)
- Clinton County
- Westchester County
- Albany County
- Columbia County
- Delaware County
- Nassau County
- Essex County
- Dutchess County
- Fulton County

**Content Categories:**

- Family & Supports
- Medical, Dental & Behavioral Health
- My Child's Condition: Disability Specific Reference
- Community Living & Recreation
- Financial, Legal & Advocacy
- Information & Referral

**Conditions Covered:**

- Epilepsy / Seizure Disorder

# Exceptional Parent Magazine



Regional Resource Guide  
of the Children and Youth with Special  
Health Care Needs (CYSHCN) Project

**Agency Name:** Exceptional Parent Magazine

**Agency Description:** Exceptional Parent magazine provides practical advice, emotional support, and the most up-to-date educational information for families of children and adults with disabilities and special healthcare needs. It has the endorsement of a professional medical society, the American Academy of Developmental Medicine and Dentistry (ADMD).

**Phone Number:**

**Email Address:**

**Website:** <http://www.epmagazine.com/>

**Counties Served:** State-Wide

**Content Categories:** Accessibility & Assistive Technology Family & Supports Information & Referral

**Conditions Covered:** Autism Spectrum Disorder (ASD) Attention-Deficit/Hyperactivity Disorder (ADHD) Behavioral / Conduct Problem Cerebral Palsy (CP) Brain Injury, Concussion, or Head Injury Down Syndrome Allergies Anxiety Arthritis Asthma Blood Disorders Cystic Fibrosis (CF) Depression Developmental Delay Diabetes Epilepsy / Seizure Disorder Genetic or Inherited Condition Deafness or Problems with Hearing Heart Condition Intellectual Disability Learning Difficulty Migraines Other Other Mental Health Condition Speech or Language Disorder Spina Bifida Substance Use Disorder Blindness or Problems with Seeing Tourette Syndrome (TS)

# Families Together in New York State (FTNYS)



Regional Resource Guide  
of the Children and Youth with Special  
Health Care Needs (CYSHCN) Project

**Agency Name:** Families Together in New York State (FTNYS)

**Agency Description:** Families Together in New York State is a family-run organization that represents families of children with social, emotional, behavioral and cross-systems challenges. We represent thousands of families from across the state whose children have been involved in many systems including mental health, substance abuse, special education, juvenile justice, and foster care.

**Phone Number:** (518) 432-0333

**Email Address:** [info@ftnys.org](mailto:info@ftnys.org)

**Website:** <http://www.ftnys.org/>

**Counties Served:** State-Wide

**Content Categories:** Community Living & Recreation, Financial, Legal & Advocacy, Information & Referral, Medical, Dental & Behavioral Health, Transitioning to Adulthood (Youth), Early Childhood & School Aged, Family & Supports

**Conditions Covered:** Attention-Deficit/Hyperactivity Disorder (ADHD), Allergies, Anxiety, Arthritis, Autism Spectrum Disorder (ASD), Asthma, Behavioral / Conduct Problem, Blood Disorders, Cerebral Palsy (CP), Cystic Fibrosis (CF), Depression, Developmental Delay, Diabetes, Down Syndrome, Epilepsy / Seizure Disorder, Genetic or Inherited Condition, Brain Injury, Concussion, or Head Injury, Deafness or Problems with Hearing, Heart Condition, Intellectual Disability, Migraines, Other Mental Health Condition, Speech or Language Disorder, Spina Bifida, Substance Use Disorder, Tourette Syndrome (TS), Blindness or Problems with Seeing, Other, Learning Difficulty



# Family Caregiver Alliance (FCA)



Regional Resource Guide  
of the Children and Youth with Special  
Health Care Needs (CYSHCN) Project

**Agency Name:** Family Caregiver Alliance (FCA)

**Agency Description:** The Family Caregiver Alliance (FCA) has supports families and friends nationwide who care for young adult loved ones with chronic, disabling health conditions. Our Family Care Navigator helps family caregivers locate public, nonprofit, and private programs and services nearest their loved one—living at home or in a residential facility. Resources include government health and disability programs, legal resources, disease-specific organizations and more.

**Phone Number:** (800) 445-8106

**Email Address:**

**Website:** [http://www.caregiver.org/state-list-views?field\\_state\\_tid=91](http://www.caregiver.org/state-list-views?field_state_tid=91)

**Counties Served:** State-Wide

**Content Categories:** Accessibility & Assistive Technology, Care Coordination, Community Living & Recreation, Financial, Legal & Advocacy, Information & Referral, Medical, Dental & Behavioral Health, Transitioning to Adulthood (Youth), Family & Supports, Early Childhood & School Aged

**Conditions Covered:** Attention-Deficit/Hyperactivity Disorder (ADHD), Allergies, Anxiety, Arthritis, Autism Spectrum Disorder (ASD), Asthma, Behavioral / Conduct Problem, Blood Disorders, Cerebral Palsy (CP), Cystic Fibrosis (CF), Depression, Developmental Delay, Diabetes, Down Syndrome, Epilepsy / Seizure Disorder, Genetic or Inherited Condition, Brain Injury, Concussion, or Head Injury, Deafness or Problems with Hearing, Heart Condition, Intellectual Disability, Migraines, Other Mental Health Condition, Speech or Language Disorder, Spina Bifida, Substance Use Disorder, Tourette Syndrome (TS), Blindness or Problems with Seeing, Other, Learning Difficulty

# Family Voices



Regional Resource Guide  
of the Children and Youth with Special  
Health Care Needs (CYSHCN) Project

**Agency Name:** Family Voices

**Agency Description:** Family Voices is a national family-led organization of families and friends of children and youth with special health care needs (CYSHCN) and disabilities. We connect a network of family organizations across the United States that provide support to families of CYSHCN. We promote partnership with families at all levels of health care—individual and policy decision-making levels—in order to improve health care services and policies for children.

**Phone Number:** (888) 835-5669

**Email Address:** [mcyr@familyvoices.org](mailto:mcyr@familyvoices.org)

**Website:** <http://familyvoices.org>

**Counties Served:** State-Wide

**Content Categories:** Accessibility & Assistive Technology Care Coordination Community Living & Recreation Financial, Legal & Advocacy Information & Referral Medical, Dental & Behavioral Health Transitioning to Adulthood (Youth) Early Childhood & School Aged Family & Supports

**Conditions Covered:** Attention-Deficit/Hyperactivity Disorder (ADHD) Allergies Anxiety Arthritis Autism Spectrum Disorder (ASD) Asthma Behavioral / Conduct Problem Blood Disorders Cerebral Palsy (CP) Cystic Fibrosis (CF) Depression Developmental Delay Diabetes Down Syndrome Epilepsy / Seizure Disorder Genetic or Inherited Condition Brain Injury, Concussion, or Head Injury Deafness or Problems with Hearing Heart Condition Intellectual Disability Migraines Other Mental Health Condition Speech or Language Disorder Spina Bifida Substance Use Disorder Tourette Syndrome (TS) Blindness or Problems with Seeing Other Learning Difficulty

# Federation for Children with Special Needs (FCSN)



Regional Resource Guide  
of the Children and Youth with Special  
Health Care Needs (CYSHCN) Project

**Agency Name:** Federation for Children with Special Needs (FCSN)

**Agency Description:** The Federation for Children with Special Needs (FCSN) provides information, support, and assistance to parents of children with disabilities, their professional partners, and their communities. We are committed to listening to and learning from families, and encouraging full participation in community life by all people, especially those with disabilities.

**Phone Number:** (617) 236-7210

**Email Address:** [info@fcsn.org](mailto:info@fcsn.org)

**Website:** <http://fcsn.org>

**Counties Served:** State-Wide

**Content Categories:** Information & Referral, Community Living & Recreation, Family & Supports, Financial, Legal & Advocacy

**Conditions Covered:** Attention-Deficit/Hyperactivity Disorder (ADHD), Allergies, Anxiety, Arthritis, Autism Spectrum Disorder (ASD), Asthma, Behavioral / Conduct Problem, Blood Disorders, Cerebral Palsy (CP), Cystic Fibrosis (CF), Depression, Developmental Delay, Diabetes, Down Syndrome, Epilepsy / Seizure Disorder, Genetic or Inherited Condition, Brain Injury, Concussion, or Head Injury, Deafness or Problems with Hearing, Heart Condition, Intellectual Disability, Migraines, Other Mental Health Condition, Speech or Language Disorder, Spina Bifida, Substance Use Disorder, Tourette Syndrome (TS), Blindness or Problems with Seeing, Other, Learning Difficulty

# Feeding Tube Awareness Foundation



Regional Resource Guide  
of the Children and Youth with Special  
Health Care Needs (CYSHCN) Project

**Agency Name:** Feeding Tube Awareness Foundation

**Agency Description:** Feeding Tube Awareness was founded in 2010 to support parents of children who are tube-fed, while raising positive awareness of tube feeding as a lifesaving medical intervention. Our mission is twofold. First, we would like to help other parents by sharing practical experience tube-feeding infants and children. Second, we would like to raise positive awareness of tube feeding so that families have the support they need.

**Phone Number:**

**Email Address:** [info@feedingtubeawareness.org](mailto:info@feedingtubeawareness.org)

**Website:** <http://www.feedingtubeawareness.org/>

**Counties Served:** State-Wide

**Content Categories:** Accessibility & Assistive Technology Family & Supports Financial, Legal & Advocacy Information & Referral  
Community Living & Recreation Early Childhood & School Aged

**Conditions Covered:** Autism Spectrum Disorder (ASD) Genetic or Inherited Condition Cerebral Palsy (CP) Other Cystic Fibrosis (CF)  
Heart Condition Diabetes Brain Injury, Concussion, or Head Injury Spina Bifida Blood Disorders

# Global Healthy Living Foundation (GHLF)



Regional Resource Guide  
of the Children and Youth with Special  
Health Care Needs (CYSHCN) Project

**Agency Name:** Global Healthy Living Foundation (GHLF)

**Agency Description:** The Global Healthy Living Foundation (GHLF) is a non-profit organization with the mission to improve the quality of life for people living with chronic illness. GHLF advocates for improved access to care at the community level, amplifying education and awareness efforts within its social media framework.

**Phone Number:** (845) 348-0400

**Email Address:** [info@ghlf.org](mailto:info@ghlf.org)

**Website:** <http://www.ghlf.org/>

**Counties Served:** [State-Wide](#)

**Content Categories:** [Information & Referral](#) [Financial, Legal & Advocacy](#)

**Conditions Covered:** [Arthritis](#) [Asthma](#) [Blood Disorders](#) [Cystic Fibrosis \(CF\)](#) [Diabetes](#) [Migraines](#) [Genetic or Inherited Condition](#) [Other](#)

# Got Transition



Regional Resource Guide  
of the Children and Youth with Special  
Health Care Needs (CYSHCN) Project

**Agency Name:** Got Transition

**Agency Description:** Got Transition aims to improve transition from pediatric to adult health care through the use of new and innovative strategies for health professionals and youth and families.

**Phone Number:** (202) 769-0486

**Email Address:** [info@GotTransition.org](mailto:info@GotTransition.org)

**Website:** <http://www.gottransition.org>

**Counties Served:** State-Wide

**Content Categories:** Transitioning to Adulthood (Youth)

**Conditions Covered:** Attention-Deficit/Hyperactivity Disorder (ADHD) Allergies Anxiety Arthritis Autism Spectrum Disorder (ASD) Asthma Behavioral / Conduct Problem Blood Disorders Cerebral Palsy (CP) Cystic Fibrosis (CF) Depression Developmental Delay Diabetes Down Syndrome Epilepsy / Seizure Disorder Genetic or Inherited Condition Brain Injury, Concussion, or Head Injury Deafness or Problems with Hearing Heart Condition Intellectual Disability Migraines Other Mental Health Condition Speech or Language Disorder Spina Bifida Substance Use Disorder Tourette Syndrome (TS) Blindness or Problems with Seeing Other Learning Difficulty

# Guide Dog Foundation for the Blind, Inc.



Regional Resource Guide  
of the Children and Youth with Special  
Health Care Needs (CYSHCN) Project

**Agency Name:** Guide Dog Foundation for the Blind, Inc.

**Agency Description:** The Guide Dog Foundation's mission is to provide guide dogs and training – free of charge – to people who are blind or visually impaired. The Guide Dog Foundation pairs each student with the dog that's right for them – and the power of their bond makes ordinary moments extraordinary.

**Phone Number:** (631) 930-9000

**Email Address:** [info@guidedog.org](mailto:info@guidedog.org)

**Website:** <http://www.guidedog.org/>

**Counties Served:** [State-Wide](#)

**Content Categories:** [Family & Supports](#) [Accessibility & Assistive Technology](#) [Community Living & Recreation](#) [Financial, Legal & Advocacy](#)  
[My Child's Condition: Disability Specific Reference](#)

**Conditions Covered:** [Blindness or Problems with Seeing](#)

# Healthy Transitions NY



Regional Resource Guide  
of the Children and Youth with Special  
Health Care Needs (CYSHCN) Project

**Agency Name:** Healthy Transitions NY

**Agency Description:** This website is for youth with developmental disabilities ages 14-25 years, family caregivers, service coordinators, and health care providers. Use this site to develop skills for transitioning from pediatric to adult healthcare. Our curriculum and tools raise awareness about developmental disabilities, improve communication, and build effective partnerships during the transition process.

**Phone Number:** (315) 464-7561

**Email Address:** [dosan@upstate.edu](mailto:dosan@upstate.edu)

**Website:** <http://healthytransitionsny.org/>

**Counties Served:** State-Wide

**Content Categories:** Care Coordination Accessibility & Assistive Technology Information & Referral Family & Supports  
Financial, Legal & Advocacy Medical, Dental & Behavioral Health

**Conditions Covered:** Developmental Delay Attention-Deficit/Hyperactivity Disorder (ADHD) Autism Spectrum Disorder (ASD)  
Cerebral Palsy (CP) Intellectual Disability Tourette Syndrome (TS) Deafness or Problems with Hearing  
Blindness or Problems with Seeing Speech or Language Disorder Learning Difficulty



# Helen Keller Services (HKS)



Regional Resource Guide  
of the Children and Youth with Special  
Health Care Needs (CYSHCN) Project

**Agency Name:** Helen Keller Services (HKS)

**Agency Description:** Helen Keller Services enables individuals who are blind, visually impaired, deaf-blind or have combined hearing and vision loss to live, work and thrive in the communities of their choice. Helen Keller Services (HKS) includes two divisions: (1) Helen Keller National Center for Deaf-Blind Youths & Adults (HKNC) and (2) Helen Keller Services for the Blind (HKSB).

**Phone Number:** (718) 522-2122

**Email Address:** [info@helenkeller.org](mailto:info@helenkeller.org)

**Website:** <http://www.helenkeller.org/hks/contact>

**Counties Served:** State-Wide

**Content Categories:** Care Coordination Accessibility & Assistive Technology Family & Supports My Child's Condition: Disability Specific Reference Transitioning to Adulthood (Youth) Community Living & Recreation

**Conditions Covered:** Blindness or Problems with Seeing Deafness or Problems with Hearing

# Hillside Family of Agencies



Regional Resource Guide  
of the Children and Youth with Special  
Health Care Needs (CYSHCN) Project

**Agency Name:** Hillside Family of Agencies

**Agency Description:** Hillside provides child welfare, mental and physical health, youth development, juvenile justice, special education and developmental disabilities services across central and western New York.

**Phone Number:** (888) 514-4455

**Email Address:** [info@hillside.com](mailto:info@hillside.com)

**Website:** <http://www.hillside.com/>

**Counties Served:** State-Wide

**Content Categories:** Accessibility & Assistive Technology, Care Coordination, Community Living & Recreation, Early Childhood & School Aged, Family & Supports, Financial, Legal & Advocacy, Information & Referral, Medical, Dental & Behavioral Health, Transitioning to Adulthood (Youth)

**Conditions Covered:** Behavioral / Conduct Problem, Anxiety, Other Mental Health Condition, Substance Use Disorder, Autism Spectrum Disorder (ASD), Attention-Deficit/Hyperactivity Disorder (ADHD), Allergies, Arthritis, Asthma, Blood Disorders, Cerebral Palsy (CP), Cystic Fibrosis (CF), Depression, Developmental Delay, Diabetes, Down Syndrome, Epilepsy / Seizure Disorder, Genetic or Inherited Condition, Brain Injury, Concussion, or Head Injury, Deafness or Problems with Hearing, Heart Condition, Intellectual Disability, Learning Difficulty, Migraines, Other, Speech or Language Disorder, Spina Bifida, Tourette Syndrome (TS), Blindness or Problems with Seeing

# Hydrocephalus Association (HA)



Regional Resource Guide  
of the Children and Youth with Special  
Health Care Needs (CYSHCN) Project

**Agency Name:** Hydrocephalus Association (HA)

**Agency Description:** The Hydrocephalus Association (HA) serves as the primary nexus for research on hydrocephalus. HA works to educate national and state policymakers, the medical community, and the general population about the nature and extent of hydrocephalus, and to focus attention on the condition and the legislation/attention needed for individuals to overcome challenges.

**Phone Number:** (888) 598-3789

**Email Address:** [Info@hydroassoc.org](mailto:Info@hydroassoc.org)

**Website:** <http://www.hydroassoc.org/>

**Counties Served:** State-Wide

**Content Categories:** Accessibility & Assistive Technology Financial, Legal & Advocacy Information & Referral  
My Child's Condition: Disability Specific Reference Family & Supports Community Living & Recreation

**Conditions Covered:** Other Brain Injury, Concussion, or Head Injury

# In Flight



Regional Resource Guide  
of the Children and Youth with Special  
Health Care Needs (CYSHCN) Project

**Agency Name:** In Flight

**Agency Description:** At In Flight, Inc. we empower people with intellectual and developmental disabilities to reach for hopes and dreams and support a meaningful quality of life.

**Phone Number:** (845) 835-6060

**Email Address:** [info@inflightinc.org](mailto:info@inflightinc.org)

**Website:** <http://www.inflightinc.org/>

**Counties Served:**

Dutchess County Ulster County Greene County Columbia County

**Content**

**Categories:**

Accessibility & Assistive Technology Care Coordination Community Living & Recreation Early Childhood & School Aged  
Family & Supports Financial, Legal & Advocacy Information & Referral Medical, Dental & Behavioral Health  
Transitioning to Adulthood (Youth)

**Conditions Covered:**

Allergies Anxiety Asthma Blood Disorders Cerebral Palsy (CP) Cystic Fibrosis (CF) Depression  
Developmental Delay Diabetes Down Syndrome Genetic or Inherited Condition Brain Injury, Concussion, or Head Injury  
Deafness or Problems with Hearing Heart Condition Intellectual Disability Learning Difficulty Migraines  
Other Mental Health Condition Speech or Language Disorder Spina Bifida Substance Use Disorder  
Tourette Syndrome (TS) Blindness or Problems with Seeing Other Attention-Deficit/Hyperactivity Disorder (ADHD)  
Arthritis Autism Spectrum Disorder (ASD) Behavioral / Conduct Problem Epilepsy / Seizure Disorder

# Inclusive Recreation Resource Center (IRRC)



Regional Resource Guide  
of the Children and Youth with Special  
Health Care Needs (CYSHCN) Project

**Agency Name:** Inclusive Recreation Resource Center (IRRC)

**Agency Description:** The mission of the Inclusive Recreation Resource Center (IRRC) is to promote and sustain participation by people of all abilities in inclusive recreation activities and resources. We have a searchable database on how inclusive and accessible recreation resources are, to help people with disabilities better plan their recreation.

**Phone Number:**

**Email Address:**

**Website:** <http://inclusiverec.org/>

**Counties Served:** State-Wide

**Content Categories:** Community Living & Recreation Accessibility & Assistive Technology Transitioning to Adulthood (Youth) Family & Supports

**Conditions Covered:** Allergies Anxiety Arthritis Asthma Attention-Deficit/Hyperactivity Disorder (ADHD) Autism Spectrum Disorder (ASD) Behavioral / Conduct Problem Blood Disorders Brain Injury, Concussion, or Head Injury Cerebral Palsy (CP) Cystic Fibrosis (CF) Depression Developmental Delay Diabetes Down Syndrome Epilepsy / Seizure Disorder Genetic or Inherited Condition Deafness or Problems with Hearing Heart Condition Intellectual Disability Learning Difficulty Migraines Other Other Mental Health Condition Speech or Language Disorder Spina Bifida Substance Use Disorder Tourette Syndrome (TS) Blindness or Problems with Seeing

# InterAgency Council (IAC) of Developmental Disabilities Agencies, Inc.



Regional Resource Guide  
of the Children and Youth with Special  
Health Care Needs (CYSHCN) Project

**Agency Name:** InterAgency Council (IAC) of Developmental Disabilities Agencies, Inc.

**Agency Description:** The InterAgency Council (IAC) of Developmental Disabilities Agencies, Inc., with over 150 members, is the largest provider association in New York for non-profit agencies that support individuals with intellectual/developmental disabilities. IAC members provide services and supports to individuals with I/DD throughout their lifespan.

**Phone Number:** (212) 645-6360

**Email Address:** [it-register@iacny.org](mailto:it-register@iacny.org)

**Website:** <http://www.iacny.org/>

**Counties Served:** State-Wide

**Content Categories:** Family & Supports, Early Childhood & School Aged, Care Coordination, Accessibility & Assistive Technology, Financial, Legal & Advocacy, Medical, Dental & Behavioral Health, Transitioning to Adulthood (Youth), Information & Referral

**Conditions Covered:** Developmental Delay, Intellectual Disability, Learning Difficulty, Attention-Deficit/Hyperactivity Disorder (ADHD), Cerebral Palsy (CP), Blindness or Problems with Seeing, Deafness or Problems with Hearing, Down Syndrome, Other, Autism Spectrum Disorder (ASD)

# Job Accommodation Network (JAN)



Regional Resource Guide  
of the Children and Youth with Special  
Health Care Needs (CYSHCN) Project

**Agency Name:** Job Accommodation Network (JAN)

**Agency Description:** The Job Accommodation Network (JAN) is the leading source of free, expert, and confidential guidance on job accommodations and disability employment issues. Serving customers across the United States and around the world for more than 35 years, JAN provides free one-on-one practical guidance and technical assistance on job accommodation solutions, Title I of the Americans with Disabilities Act (ADA) and related legislation, and self-employment and entrepreneurship options for people with disabilities

**Phone Number:** (800) 526-7234

**Email Address:** [jan@askjan.org](mailto:jan@askjan.org)

**Website:** <https://askjan.org/>

**Counties Served:** State-Wide

**Content Categories:** Information & Referral Transitioning to Adulthood (Youth) Financial, Legal & Advocacy

**Conditions Covered:** Allergies Anxiety Arthritis Asthma Attention-Deficit/Hyperactivity Disorder (ADHD) Autism Spectrum Disorder (ASD) Behavioral / Conduct Problem Blindness or Problems with Seeing Blood Disorders Brain Injury, Concussion, or Head Injury Cerebral Palsy (CP) Cystic Fibrosis (CF) Deafness or Problems with Hearing Depression Developmental Delay Diabetes Down Syndrome Epilepsy / Seizure Disorder Genetic or Inherited Condition Heart Condition Intellectual Disability Learning Difficulty Migraines Other Other Mental Health Condition Speech or Language Disorder Spina Bifida Substance Use Disorder Tourette Syndrome (TS)

# Juvenile Diabetes Research Foundation (JDRF)



Regional Resource Guide  
of the Children and Youth with Special  
Health Care Needs (CYSHCN) Project

**Agency Name:** Juvenile Diabetes Research Foundation (JDRF)

**Agency Description:** JDRF is the leading global organization funding type 1 diabetes (T1D) research. From funding innovative research to advocating for government action to providing a support structure for our community, no other organization does more to fight T1D than JDRF.

**Phone Number:** (800) 533-2873

**Email Address:** [info@jdrf.org](mailto:info@jdrf.org)

**Website:** <http://www.jdrf.org/chapter-finder/>

**Counties Served:** [State-Wide](#)

**Content Categories:** [Accessibility & Assistive Technology](#) [Community Living & Recreation](#) [Early Childhood & School Aged](#) [Information & Referral](#) [My Child's Condition: Disability Specific Reference](#) [Financial, Legal & Advocacy](#) [Family & Supports](#)

**Conditions Covered:** [Diabetes](#)



# Kessler Foundation



Regional Resource Guide  
of the Children and Youth with Special  
Health Care Needs (CYSHCN) Project

**Agency Name:** Kessler Foundation

**Agency Description:** The mission of Kessler Foundation is to improve quality of life for people with disabilities through discovery, innovation, demonstration, application, and dissemination. Kessler Foundation leads the way in linking science and grantsmanship so that people living with disabilities can lead more productive, independent, and fulfilling lives.

**Phone Number:** (973) 324-8362

**Email Address:** [info@kesslerfoundation.org](mailto:info@kesslerfoundation.org)

**Website:** <http://kesslerfoundation.org/>

**Counties Served:** State-Wide

**Content Categories:** Financial, Legal & Advocacy Information & Referral Transitioning to Adulthood (Youth)

**Conditions Covered:** Cerebral Palsy (CP) Brain Injury, Concussion, or Head Injury Attention-Deficit/Hyperactivity Disorder (ADHD) Autism Spectrum Disorder (ASD) Other

# Kids Enjoy Exercise Now (KEEN)



Regional Resource Guide  
of the Children and Youth with Special  
Health Care Needs (CYSHCN) Project

**Agency Name:** Kids Enjoy Exercise Now (KEEN)

**Agency Description:** KEEN provides free recreational opportunities to children and young adults with disabilities by pairing them with trained volunteers for fun, non competitive activities. KEEN seeks to develop each athlete's self-esteem and confidence, as well as recreational skills and talents, and to increase each athlete's ability to participate in a broader range of recreational activities and environments.

**Phone Number:** (212) 768-6785

**Email Address:** [info@keennewyork.org](mailto:info@keennewyork.org)

**Website:** <http://www.keennewyork.org>

**Counties Served:** State-Wide

**Content Categories:** Community Living & Recreation

**Conditions Covered:** Developmental Delay, Autism Spectrum Disorder (ASD), Intellectual Disability, Other, Learning Difficulty, Blood Disorders, Cerebral Palsy (CP), Cystic Fibrosis (CF), Arthritis, Anxiety, Allergies, Attention-Deficit/Hyperactivity Disorder (ADHD), Asthma, Behavioral / Conduct Problem, Depression, Diabetes, Down Syndrome, Epilepsy / Seizure Disorder, Genetic or Inherited Condition, Brain Injury, Concussion, or Head Injury, Deafness or Problems with Hearing, Heart Condition, Migraines, Other Mental Health Condition, Speech or Language Disorder, Spina Bifida, Substance Use Disorder, Tourette Syndrome (TS)

# Learning Disabilities Association of America (LDA)



Regional Resource Guide  
of the Children and Youth with Special  
Health Care Needs (CYSHCN) Project

**Agency Name:** Learning Disabilities Association of America (LDA)

**Agency Description:** LDA's mission is to create opportunities for success for all individuals affected by learning disabilities through support, education, and advocacy. We provide support to people with learning disabilities, their parents, teachers and other professionals with cutting edge information on learning disabilities, practical solutions, and a comprehensive network of resources.

**Phone Number:** (412) 341-1515

**Email Address:** [info@LDAAmerica.org](mailto:info@LDAAmerica.org)

**Website:** <http://www.ldaamerica.org>

**Counties Served:** State-Wide

**Content Categories:** Early Childhood & School Aged Family & Supports Information & Referral Financial, Legal & Advocacy

**Conditions Covered:** Learning Difficulty Attention-Deficit/Hyperactivity Disorder (ADHD) Other

# Lighthouse Guild



Regional Resource Guide  
of the Children and Youth with Special  
Health Care Needs (CYSHCN) Project

**Agency Name:** Lighthouse Guild

**Agency Description:** Lighthouse Guild offers other programs and resources for parents and teens with our tele-support groups. Through our National Tele-Support Network for Parents of Children with Visual Impairment, you can connect with other parents to share resources, experiences, strength, and hope, and our Youth Transition Program helps students prepare for life after high school, including the transition to college.

**Phone Number:** (212) 769-6318

**Email Address:**

**Website:** <http://www.lighthouseguild.org/>

**Counties Served:** State-Wide

**Content Categories:** Family & Supports, Accessibility & Assistive Technology, Information & Referral, Transitioning to Adulthood (Youth), My Child's Condition: Disability Specific Reference, Medical, Dental & Behavioral Health, Financial, Legal & Advocacy, Community Living & Recreation

**Conditions Covered:** Blindness or Problems with Seeing

# Lincoln Center Passport to the Arts



Regional Resource Guide  
of the Children and Youth with Special  
Health Care Needs (CYSHCN) Project

**Agency Name:** Lincoln Center Passport to the Arts

**Agency Description:** Designed for children, teens, and adults with disabilities and their families, Passport to the Arts provides a welcoming, accessible, and affordable introduction to the performing arts at Lincoln Center at no cost. Families will receive pre-visit materials, including social narratives, photos, and links, before each program. All programs currently take place via Zoom.

**Phone Number:** (212) 875-5375

**Email Address:** [access@lincolncenter.org](mailto:access@lincolncenter.org)

**Website:** <http://lincolncenter.org/lincoln-center-at-home/series/passport-to-the-arts>

**Counties Served:** State-Wide

**Content Categories:** Community Living & Recreation Accessibility & Assistive Technology Family & Supports

**Conditions Covered:** Allergies Anxiety Arthritis Asthma Attention-Deficit/Hyperactivity Disorder (ADHD) Autism Spectrum Disorder (ASD) Behavioral / Conduct Problem Blood Disorders Brain Injury, Concussion, or Head Injury Cerebral Palsy (CP) Cystic Fibrosis (CF) Depression Developmental Delay Diabetes Down Syndrome Epilepsy / Seizure Disorder Genetic or Inherited Condition Deafness or Problems with Hearing Heart Condition Intellectual Disability Learning Difficulty Migraines Other Other Mental Health Condition Speech or Language Disorder Spina Bifida Substance Use Disorder Tourette Syndrome (TS) Blindness or Problems with Seeing

# Little People of America (LPA)



Regional Resource Guide  
of the Children and Youth with Special  
Health Care Needs (CYSHCN) Project

**Agency Name:** Little People of America (LPA)

**Agency Description:** LPA is dedicated to improving the quality of life for people with dwarfism throughout their lives while celebrating with great pride Little People's contribution to social diversity. District 2 includes New York.

**Phone Number:** (714) 368-3689

**Email Address:** [director@lpadistrict2.org](mailto:director@lpadistrict2.org)

**Website:** <http://www.lpaonline.org/district-2-nj-ny-pa>

**Counties Served:** State-Wide

**Content Categories:** Community Living & Recreation Family & Supports Financial, Legal & Advocacy Information & Referral  
My Child's Condition: Disability Specific Reference Transitioning to Adulthood (Youth)

**Conditions Covered:** Genetic or Inherited Condition Other

# Live Accessible



Regional Resource Guide  
of the Children and Youth with Special  
Health Care Needs (CYSHCN) Project

**Agency Name:** Live Accessible

**Agency Description:** We are a resource for individuals and families with blindness or low vision who want to live a more accessible life, created by a family who are all visually impaired and blind themselves.

This website is an ongoing list of resources for those with sight loss. We have a YouTube channel called Live Accessible with videos on tips, how-tos, and advice with new videos every week.

**Phone Number:**

**Email Address:**

**Website:** <http://liveaccessible.com/>

**Counties Served:** State-Wide

**Content Categories:** Information & Referral Accessibility & Assistive Technology My Child's Condition: Disability Specific Reference

**Conditions Covered:** Blindness or Problems with Seeing

# Living Resources



Regional Resource Guide  
of the Children and Youth with Special  
Health Care Needs (CYSHCN) Project

**Agency Name:** Living Resources

**Agency Description:** Living Resources is dedicated to providing life enhancing services to individuals challenged by intellectual and developmental disabilities, as well as those who are brain injury survivors. We offer a safe and nurturing environment that allows individuals to meet and exceed their personal goals.

**Phone Number:** (518) 218-0000

**Email Address:**

**Website:** <http://www.livingresources.org>

**Counties Served:** State-Wide

**Content Categories:** Community Living & Recreation Medical, Dental & Behavioral Health

**Conditions Covered:** Brain Injury, Concussion, or Head Injury Intellectual Disability Developmental Delay Learning Difficulty Cerebral Palsy (CP) Attention-Deficit/Hyperactivity Disorder (ADHD) Autism Spectrum Disorder (ASD) Down Syndrome Tourette Syndrome (TS) Genetic or Inherited Condition



# Making Authentic Friendships (MAF)



Regional Resource Guide  
of the Children and Youth with Special  
Health Care Needs (CYSHCN) Project

**Agency Name:** Making Authentic Friendships (MAF)

**Agency Description:** Making Authentic Friendships' responsive web-based application helps individuals with special needs (age 13 and older) find friends at home or on the go, based off of their geolocation, diagnosis, age, and interests. It works like a game, is interactive, fun, and user friendly.

**Phone Number:** (631) 374-0518

**Email Address:**

**Website:** <http://makingauthenticfriendships.com/>

**Counties Served:** State-Wide

**Content Categories:** Family & Supports Accessibility & Assistive Technology Transitioning to Adulthood (Youth)

**Conditions Covered:** Blindness or Problems with Seeing Autism Spectrum Disorder (ASD) Behavioral / Conduct Problem Depression Cerebral Palsy (CP) Developmental Delay Genetic or Inherited Condition Epilepsy / Seizure Disorder Intellectual Disability Down Syndrome Other Mental Health Condition Speech or Language Disorder Other Attention-Deficit/Hyperactivity Disorder (ADHD) Allergies Anxiety Arthritis Asthma Blood Disorders Cystic Fibrosis (CF) Diabetes Brain Injury, Concussion, or Head Injury Deafness or Problems with Hearing Heart Condition Learning Difficulty Migraines Spina Bifida Substance Use Disorder Tourette Syndrome (TS)

# Medical Directory of New York State



Regional Resource Guide  
of the Children and Youth with Special  
Health Care Needs (CYSHCN) Project

**Agency Name:** Medical Directory of New York State

**Agency Description:** The information listed is extracted from the Medical Society of the State of New York physician database used in production of the Medical Directory of New York State. The MSSNY Physician Lookup service includes only current members of the Medical Society of the State of New York (MSSNY).

**Phone Number:** (516) 488-6100

**Email Address:** [mssny@mssny.org](mailto:mssny@mssny.org)

**Website:** [http://www.mssny.org/MSSNY/Doc\\_Lookup/Default.aspx](http://www.mssny.org/MSSNY/Doc_Lookup/Default.aspx)

**Counties Served:** State-Wide

**Content Categories:** Information & Referral Medical, Dental & Behavioral Health

**Conditions Covered:** Attention-Deficit/Hyperactivity Disorder (ADHD) Allergies Anxiety Arthritis Autism Spectrum Disorder (ASD) Asthma Behavioral / Conduct Problem Blood Disorders Cerebral Palsy (CP) Cystic Fibrosis (CF) Depression Developmental Delay Diabetes Down Syndrome Epilepsy / Seizure Disorder Genetic or Inherited Condition Brain Injury, Concussion, or Head Injury Deafness or Problems with Hearing Heart Condition Intellectual Disability Migraines Other Mental Health Condition Speech or Language Disorder Spina Bifida Substance Use Disorder Tourette Syndrome (TS) Blindness or Problems with Seeing Other Learning Difficulty

# Mental Health Association of New York State (MHANYS)



Regional Resource Guide  
of the Children and Youth with Special  
Health Care Needs (CYSHCN) Project

**Agency Name:** Mental Health Association of New York State (MHANYS)

**Agency Description:** MHANYS is a not-for-profit organization that works to end the stigma against mental illness and promotes mental health wellness in New York State. MHANYS achieves this through training, education, advocacy and policy, community-based partnership programming, and by connecting individuals and families to help.

**Phone Number:** (518) 434-0439

**Email Address:** [info@mhany.org](mailto:info@mhany.org)

**Website:** <http://mhany.org/>

**Counties Served:** State-Wide

**Content Categories:** Accessibility & Assistive Technology, Care Coordination, Community Living & Recreation, Financial, Legal & Advocacy, Information & Referral, Medical, Dental & Behavioral Health, Transitioning to Adulthood (Youth), Early Childhood & School Aged, Family & Supports

**Conditions Covered:** Depression, Anxiety, Other Mental Health Condition

Regional Resource Guide  
of the Children and Youth with Special  
Health Care Needs (CYSHCN) Project

**Agency Name:** myFace

**Agency Description:** myFace is a leading nonprofit organization dedicated to changing the faces - and transforming the lives - of children and adults with facial differences. For 70 years, myFace has focused on providing access to holistic comprehensive care, education, resources, and support that pave the way for better outcomes for those impacted by craniofacial conditions.

**Phone Number:** (917) 720-4701

**Email Address:** [info@myface.org](mailto:info@myface.org)

**Website:** <http://www.myface.org/>

**Counties Served:** [State-Wide](#)

**Content Categories:** [Family & Supports](#) [Community Living & Recreation](#) [Information & Referral](#) [Medical, Dental & Behavioral Health](#)  
[Financial, Legal & Advocacy](#) [My Child's Condition: Disability Specific Reference](#)

**Conditions Covered:** [Other](#) [Genetic or Inherited Condition](#)

# National Alliance on Mental Illness (NAMI)



Regional Resource Guide  
of the Children and Youth with Special  
Health Care Needs (CYSHCN) Project

**Agency Name:** National Alliance on Mental Illness (NAMI)

**Agency Description:** NAMI is an association of more than 500 local affiliates. They work to raise awareness and provide support and education to those with mental illness. NAMI has support groups, helplines, and various chapters across New York.

**Phone Number:** (518) 462-2000

**Email Address:** [info@naminys.org](mailto:info@naminys.org)

**Website:** <http://www.naminys.org>

**Counties Served:** State-Wide

**Content Categories:** Family & Supports Information & Referral Financial, Legal & Advocacy Transitioning to Adulthood (Youth) Community Living & Recreation

**Conditions Covered:** Anxiety Depression Other Mental Health Condition

# National Association of the Deaf (NAD)



Regional Resource Guide  
of the Children and Youth with Special  
Health Care Needs (CYSHCN) Project

**Agency Name:** National Association of the Deaf (NAD)

**Agency Description:** The mission of the National Association of the Deaf is to preserve, protect and promote the civil, human and linguistic rights of deaf and hard of hearing people in the United States of America. Provides contact information for the Empire State Association of the Deaf (ESAD) in New York and the following directories: (1) State Agencies of Deaf and Hard of Hearing (2) ASL at Universities (3) Senior Resources and (4) Statewide Vocational Rehabilitation Services.

**Phone Number:** (301) 587-1788

**Email Address:** [nad.info@nad.org](mailto:nad.info@nad.org)

**Website:** <http://www.nad.org/>

**Counties Served:** State-Wide

**Content Categories:** Information & Referral Transitioning to Adulthood (Youth) My Child's Condition: Disability Specific Reference  
Financial, Legal & Advocacy Accessibility & Assistive Technology Community Living & Recreation Family & Supports

**Conditions Covered:** Deafness or Problems with Hearing

# National Autism Association (NAA)



Regional Resource Guide  
of the Children and Youth with Special  
Health Care Needs (CYSHCN) Project

**Agency Name:** National Autism Association (NAA)

**Agency Description:** The mission of the National Autism Association is (NAA) to respond to the most urgent needs of the autism community, providing real help and hope so that all affected can reach their full potential. NAA has New York Metro chapter, proudly serve the five boroughs of New York City, Long Island, Westchester County, and Rockland County.

**Phone Number:** (877) 622-2884

**Email Address:** [naa@nationalautism.org](mailto:naa@nationalautism.org)

**Website:** <http://nationalautismassociation.org/resources/naa-local-chapters/>

**Counties Served:** State-Wide

**Content Categories:** Financial, Legal & Advocacy Family & Supports Community Living & Recreation Early Childhood & School Aged  
My Child's Condition: Disability Specific Reference Transitioning to Adulthood (Youth) Information & Referral

**Conditions Covered:** Autism Spectrum Disorder (ASD)

# National Center for Learning Disabilities (NCLD)



Regional Resource Guide  
of the Children and Youth with Special  
Health Care Needs (CYSHCN) Project

**Agency Name:** National Center for Learning Disabilities (NCLD)

**Agency Description:** NCLD works every day to make meaningful change for individuals with learning and attention issues. Our work includes advocacy, research, scholarship and awards, and young adult initiatives.

**Phone Number:** (888) 575-7373

**Email Address:** [info@nclld.org](mailto:info@nclld.org)

**Website:** <http://www.nclld.org>

**Counties Served:** State-Wide

**Content Categories:** Financial, Legal & Advocacy Transitioning to Adulthood (Youth) Early Childhood & School Aged  
Community Living & Recreation Family & Supports Information & Referral

**Conditions Covered:** Attention-Deficit/Hyperactivity Disorder (ADHD) Learning Difficulty



# National Center on Health, Physical Activity and Disability (NCHPAD)



Regional Resource Guide  
of the Children and Youth with Special  
Health Care Needs (CYSHCN) Project

**Agency Name:** National Center on Health, Physical Activity and Disability (NCHPAD)

**Agency Description:** NCHPAD is the premier resource for information on physical activity, health promotion, and disability, serving persons with physical, sensory and cognitive disabilities across the lifespan. NCHPAD features a variety of resources and services which can benefit all ages and populations in New York.

**Phone Number:** (888) 900-8086

**Email Address:** [email@nchpad.org](mailto:email@nchpad.org)

**Website:** <http://www.nchpad.org/Directories/Youth/USA/New~York>

**Counties Served:** State-Wide

**Content Categories:** Community Living & Recreation Transitioning to Adulthood (Youth) Family & Supports Information & Referral

**Conditions Covered:** Cerebral Palsy (CP) Autism Spectrum Disorder (ASD) Developmental Delay Down Syndrome Epilepsy / Seizure Disorder Intellectual Disability Learning Difficulty Other Attention-Deficit/Hyperactivity Disorder (ADHD) Allergies Anxiety Arthritis Asthma Behavioral / Conduct Problem Blood Disorders Brain Injury, Concussion, or Head Injury Cystic Fibrosis (CF) Depression Diabetes Genetic or Inherited Condition Deafness or Problems with Hearing Heart Condition Other Mental Health Condition Speech or Language Disorder Spina Bifida Tourette Syndrome (TS) Blindness or Problems with Seeing

# National Collaborative on Workforce and Disability for Youth (NCWD/Youth)



Regional Resource Guide  
of the Children and Youth with Special  
Health Care Needs (CYSHCN) Project

**Agency Name:** National Collaborative on Workforce and Disability for Youth (NCWD/Youth)

**Agency Description:** NCWD/Youth works to ensure that transition age youth are provided full access to high quality services in integrated settings to gain education, employment and independent living. NCWD/Youth offers a variety of publications and tip sheets to help youth, make informed choices about their futures.

**Phone Number:** (877) 871-0744

**Email Address:**

**Website:** <http://www.ncwd-youth.info/>

**Counties Served:** State-Wide

**Content Categories:** Accessibility & Assistive Technology Community Living & Recreation Care Coordination Family & Supports Information & Referral Transitioning to Adulthood (Youth) Financial, Legal & Advocacy

**Conditions Covered:** Attention-Deficit/Hyperactivity Disorder (ADHD) Developmental Delay Learning Difficulty Intellectual Disability Allergies Anxiety Arthritis Asthma Autism Spectrum Disorder (ASD) Behavioral / Conduct Problem Blood Disorders Brain Injury, Concussion, or Head Injury Cerebral Palsy (CP) Cystic Fibrosis (CF) Depression Diabetes Down Syndrome Epilepsy / Seizure Disorder Genetic or Inherited Condition Deafness or Problems with Hearing Heart Condition Migraines Other Other Mental Health Condition Speech or Language Disorder Spina Bifida Substance Use Disorder Tourette Syndrome (TS) Blindness or Problems with Seeing

# National Down Syndrome Society (NDSS)



Regional Resource Guide  
of the Children and Youth with Special  
Health Care Needs (CYSHCN) Project

**Agency Name:** National Down Syndrome Society (NDSS)

**Agency Description:** The National Down Syndrome Society envisions a world in which all people with Down Syndrome have the opportunity to enhance their quality of life, realize their life aspirations and become valued members of welcoming communities. NDSS supports and advocates for the Down syndrome community by focusing on three key areas of programming: Resources & Support, Policy & Advocacy, and Community Engagement.

**Phone Number:** (800) 221-4602

**Email Address:** [info@ndss.org](mailto:info@ndss.org)

**Website:** <http://www.ndss.org/>

**Counties Served:** State-Wide

**Content Categories:** Family & Supports, Community Living & Recreation, Financial, Legal & Advocacy, My Child's Condition: Disability Specific Reference, Information & Referral, Transitioning to Adulthood (Youth)

**Conditions Covered:** Down Syndrome

# National Eating Disorders Association (NEDA)



Regional Resource Guide  
of the Children and Youth with Special  
Health Care Needs (CYSHCN) Project

**Agency Name:** National Eating Disorders Association (NEDA)

**Agency Description:** The National Eating Disorders Association (NEDA) is the largest nonprofit organization dedicated to supporting individuals and families affected by eating disorders. NEDA supports individuals and families affected by eating disorders, and serves as a catalyst for prevention, cures and access to quality care.

**Phone Number:** (212) 575-6200

**Email Address:** [info@NationalEatingDisorders.org](mailto:info@NationalEatingDisorders.org)

**Website:** <http://www.nationaleatingdisorders.org/>

**Counties Served:** State-Wide

**Content Categories:** Information & Referral Family & Supports My Child's Condition: Disability Specific Reference  
Community Living & Recreation Medical, Dental & Behavioral Health

**Conditions Covered:** Other Mental Health Condition

# National Federation of the Blind of New York State (NFB of NYS)



Regional Resource Guide  
of the Children and Youth with Special  
Health Care Needs (CYSHCN) Project

**Agency Name:** National Federation of the Blind of New York State (NFB of NYS)

**Agency Description:** The National Federation of the Blind is the only organization that believes in the full capacity of blind people and has the power, influence, diversity, and determination to help transform dreams into reality. We offer many programs, services, and resources for parents of blind children. NFB has NYS-specific chapters, divisions, and groups.

**Phone Number:** (716) 222-3632

**Email Address:** [president@nfbny.org](mailto:president@nfbny.org)

**Website:** <http://nfbny.org/>

**Counties Served:** State-Wide

**Content Categories:** Family & Supports Information & Referral My Child's Condition: Disability Specific Reference Financial, Legal & Advocacy  
Community Living & Recreation

**Conditions Covered:** Blindness or Problems with Seeing

# National Institute of Mental Health (NIMH)



Regional Resource Guide  
of the Children and Youth with Special  
Health Care Needs (CYSHCN) Project

**Agency Name:** National Institute of Mental Health (NIMH)

**Agency Description:** The NIMH is the lead federal agency for research on mental behaviors and disorders. Its mission is to reduce the burden of these conditions through research on mind, brain and behavior which will lead to better prevention and recovery from mental disorders. It provides information on mental disorders and lists clinical trials in progress.

**Phone Number:** (866) 615-6464

**Email Address:** [nimhinfo@nih.gov](mailto:nimhinfo@nih.gov)

**Website:** <http://www.nimh.nih.gov/index.shtml>

**Counties Served:** State-Wide

**Content Categories:** Government Agency Information & Referral Financial, Legal & Advocacy Medical, Dental & Behavioral Health

**Conditions Covered:** Other Mental Health Condition Anxiety Depression Substance Use Disorder Other Genetic or Inherited Condition Attention-Deficit/Hyperactivity Disorder (ADHD) Autism Spectrum Disorder (ASD)

# National Multiple Sclerosis (MS) Society



Regional Resource Guide  
of the Children and Youth with Special  
Health Care Needs (CYSHCN) Project

**Agency Name:** National Multiple Sclerosis (MS) Society

**Agency Description:** The National Multiple Sclerosis (MS) Society is a gathering place for people with MS, their family and loved ones, healthcare providers, volunteers, donors, fundraisers, advocates, community leaders and all those that seek a world free of MS. In order to change the world, we mobilize all possible human and financial resources to achieve results.

**Phone Number:** (800) 344-4867

**Email Address:**

**Website:** <http://www.nationalmssociety.org/Chapters?chapters=6535,6536,6537>

**Counties Served:** State-Wide

**Content Categories:** Information & Referral, Family & Supports, My Child's Condition: Disability Specific Reference, Financial, Legal & Advocacy, Community Living & Recreation

**Conditions Covered:** Other

# National Organization for Albinism and Hypopigmentation (NOAH)



Regional Resource Guide  
of the Children and Youth with Special  
Health Care Needs (CYSHCN) Project

**Agency Name:** National Organization for Albinism and Hypopigmentation (NOAH)

**Agency Description:** NOAH serves the albinism community by providing information and support. NOAH's mission is to act as a conduit for accurate and authoritative information about all aspects of living with albinism and to provide a place where people with albinism and their families in the U.S. and Canada can find acceptance, support and fellowship.

**Phone Number:** (800) 473-2310

**Email Address:** [info@albinism.org](mailto:info@albinism.org)

**Website:** <http://www.albinism.org/>

**Counties Served:** [State-Wide](#)

**Content Categories:** [Information & Referral](#) [Financial, Legal & Advocacy](#) [Family & Supports](#) [My Child's Condition: Disability Specific Reference](#)  
[Community Living & Recreation](#) [Transitioning to Adulthood \(Youth\)](#)

**Conditions Covered:** [Other](#) [Genetic or Inherited Condition](#)



# National Organization on Fetal Alcohol Syndrome (NOFAS)



Regional Resource Guide  
of the Children and Youth with Special  
Health Care Needs (CYSHCN) Project

**Agency Name:** National Organization on Fetal Alcohol Syndrome (NOFAS)

**Agency Description:** The National Organization on Fetal Alcohol Syndrome (NOFAS) is the leading voice and resource of the Fetal Alcohol Spectrum Disorders (FASD) community. NOFAS effectively increases public awareness and mobilizes grassroots action in diverse communities and represents the interests of persons with FASD and their caregivers as the liaison to researchers and policymakers. NOFAS strives to reduce the stigma and improve the quality of life for affected individuals and families.

**Phone Number:** (202) 785-4585

**Email Address:** [information@nofas.org](mailto:information@nofas.org)

**Website:** <http://www.nofas.org/state-resources-for-new-york>

**Counties Served:** State-Wide

**Content Categories:** Family & Supports, Information & Referral, My Child's Condition: Disability Specific Reference, Financial, Legal & Advocacy, Community Living & Recreation

**Conditions Covered:** Other Mental Health Condition, Substance Use Disorder

# National Organization Rare Diseases (NORD)



Regional Resource Guide  
of the Children and Youth with Special  
Health Care Needs (CYSHCN) Project

**Agency Name:** National Organization Rare Diseases (NORD)

**Agency Description:** NORD is a patient advocacy organization dedicated to individuals with rare diseases and the organizations that serve them. NORD, along with its more than 300 patient organization members, is committed to the identification, treatment, and cure of rare disorders through programs of education, advocacy, research, and patient services.

**Phone Number:** (800) 999-6673

**Email Address:**

**Website:** <http://rarediseases.org/>

**Counties Served:** State-Wide

**Content Categories:** Family & Supports Information & Referral Financial, Legal & Advocacy Medical, Dental & Behavioral Health

**Conditions Covered:** Epilepsy / Seizure Disorder Cerebral Palsy (CP) Spina Bifida Cystic Fibrosis (CF) Genetic or Inherited Condition Blood Disorders Down Syndrome Tourette Syndrome (TS) Blindness or Problems with Seeing Heart Condition Diabetes Behavioral / Conduct Problem Brain Injury, Concussion, or Head Injury

# National Suicide Prevention Lifeline



Regional Resource Guide  
of the Children and Youth with Special  
Health Care Needs (CYSHCN) Project

**Agency Name:** National Suicide Prevention Lifeline

**Agency Description:** The Lifeline provides 24/7, free and confidential support for people in distress, prevention and crisis resources for you or your loved ones, and best practices for professionals. The National Suicide Prevention Lifeline has a Spanish Language line at 1-888-628-9454. We also provide the Tele-Interpreters service to our crisis centers, which supports over 150 languages.

**Phone Number:** (800) 273-8255

**Email Address:**

**Website:** <http://suicidepreventionlifeline.org/>

**Counties Served:** State-Wide

**Content Categories:** Accessibility & Assistive Technology Family & Supports Information & Referral Transitioning to Adulthood (Youth)  
Medical, Dental & Behavioral Health

**Conditions Covered:** Anxiety Behavioral / Conduct Problem Depression Other Mental Health Condition Substance Use Disorder

# New York Alliance for Inclusion and Innovation (NY Alliance)



Regional Resource Guide  
of the Children and Youth with Special  
Health Care Needs (CYSHCN) Project

**Agency Name:** New York Alliance for Inclusion and Innovation (NY Alliance)

**Agency Description:** The New York Alliance for Inclusion and Innovation (NY Alliance) serves as a catalyst for positive change and a leading resource for individuals with disabilities, their families, and their organizations. We do this through: advocacy, education & training, technical assistance & practice improvement, advancing sound public policy.

**Phone Number:** (518) 795-3590

**Email Address:**

**Website:** <http://nyalliance.org/>

**Counties Served:** State-Wide

**Content Categories:** Financial, Legal & Advocacy Family & Supports Information & Referral

**Conditions Covered:** Allergies Anxiety Arthritis Asthma Attention-Deficit/Hyperactivity Disorder (ADHD) Autism Spectrum Disorder (ASD) Behavioral / Conduct Problem Blindness or Problems with Seeing Blood Disorders Brain Injury, Concussion, or Head Injury Cerebral Palsy (CP) Cystic Fibrosis (CF) Deafness or Problems with Hearing Depression Developmental Delay Diabetes Down Syndrome Epilepsy / Seizure Disorder Genetic or Inherited Condition Heart Condition Intellectual Disability Learning Difficulty Migraines Other Other Mental Health Condition Speech or Language Disorder Spina Bifida Substance Use Disorder Tourette Syndrome (TS)

# New York Deaf-Blind Collaborative (NYDBC)



Regional Resource Guide  
of the Children and Youth with Special  
Health Care Needs (CYSHCN) Project

**Agency Name:** New York Deaf-Blind Collaborative (NYDBC)

**Agency Description:** NYDBC is a statewide project that provides technical assistance to professionals and families on behalf of children and young adults who are deaf-blind between the ages of 0–21. The project is funded by the Office of Special Education Programs (OSEP) through the CUNY Research Foundation and is housed at Queens College in Flushing, NY. Any and all interested parties in New York State can access NYDBC, free of charge, as a resource on deaf-blindness.

**Phone Number:** (718) 997-4856

**Email Address:** nydbc@qc.cuny.edu

**Website:** <http://nydeafblind.org/>

**Counties Served:** State-Wide

**Content Categories:** Accessibility & Assistive Technology Information & Referral Family & Supports Early Childhood & School Aged  
Transitioning to Adulthood (Youth) My Child's Condition: Disability Specific Reference

**Conditions Covered:** Deafness or Problems with Hearing Blindness or Problems with Seeing

# New York Housing Resource Center (HRC) for People with Intellectual / Developmental Disabilities (I/DD)



Regional Resource Guide  
of the Children and Youth with Special  
Health Care Needs (CYSHCN) Project

**Agency Name:** New York Housing Resource Center (HRC) for People with Intellectual / Developmental Disabilities (I/DD)

**Agency Description:** The New York Housing Resource Center (HRC) for People with Intellectual / Developmental Disabilities (I/DD) was developed by New York Alliance for Inclusion & Innovation. The HRC acts as a clearinghouse for information and resources to foster collaboration between and among the housing industry and people with I/DD, and provides community training for people with I/DD and their families.

**Phone Number:** (929) 260-3877

**Email Address:** [info@nyhrc.org](mailto:info@nyhrc.org)

**Website:** <http://nyhrc.org/>

**Counties Served:** State-Wide

**Content Categories:** Family & Supports, Information & Referral, Financial, Legal & Advocacy, Transitioning to Adulthood (Youth), Community Living & Recreation

**Conditions Covered:** Developmental Delay, Intellectual Disability, Attention-Deficit/Hyperactivity Disorder (ADHD), Autism Spectrum Disorder (ASD), Blindness or Problems with Seeing, Cerebral Palsy (CP), Deafness or Problems with Hearing, Down Syndrome, Epilepsy / Seizure Disorder, Genetic or Inherited Condition, Learning Difficulty, Speech or Language Disorder, Tourette Syndrome (TS)

# New York Legal Assistance Group (NYLAG)



Regional Resource Guide  
of the Children and Youth with Special  
Health Care Needs (CYSHCN) Project

**Agency Name:** New York Legal Assistance Group (NYLAG)

**Agency Description:** The New York Legal Assistance Group (NYLAG) uses the power of the law to help New Yorkers in need combat social and economic injustice. We address emerging and urgent legal needs with comprehensive, free civil legal services, impact litigation, policy advocacy, and community education.

**Phone Number:** (212) 613-5000

**Email Address:** [info@nylag.org](mailto:info@nylag.org)

**Website:** <http://www.nylag.org/>

**Counties Served:** State-Wide

**Content Categories:** Financial, Legal & Advocacy Information & Referral

**Conditions Covered:** Developmental Delay Other Attention-Deficit/Hyperactivity Disorder (ADHD) Allergies Anxiety Arthritis Asthma Autism Spectrum Disorder (ASD) Behavioral / Conduct Problem Blood Disorders Cerebral Palsy (CP) Cystic Fibrosis (CF) Depression Diabetes Down Syndrome Epilepsy / Seizure Disorder Genetic or Inherited Condition Brain Injury, Concussion, or Head Injury Deafness or Problems with Hearing Heart Condition Intellectual Disability Learning Difficulty Migraines Other Mental Health Condition Speech or Language Disorder Spina Bifida Substance Use Disorder Tourette Syndrome (TS) Blindness or Problems with Seeing

# New York Mid-Atlantic Caribbean Regional Genetics Network (NYMAC)



Regional Resource Guide  
of the Children and Youth with Special  
Health Care Needs (CYSHCN) Project

**Agency Name:** New York Mid-Atlantic Caribbean Regional Genetics Network (NYMAC)

**Agency Description:** The New York-Mid-Atlantic-Caribbean (NYMAC) Regional Genetics Network is one of seven Regional Genetics Networks in the country. Individuals from our region with genetic disease and their families, advocates, healthcare professionals and public health professionals collaborate to ensure that individuals with heritable disorders and their families have access to quality care and appropriate genetic expertise.

**Phone Number:**

**Email Address:** NYMAC@ferre.org

**Website:** <http://nymacgenetics.org/>

**Counties Served:** State-Wide

**Content Categories:** Family & Supports My Child's Condition: Disability Specific Reference Information & Referral  
Community Living & Recreation

**Conditions Covered:** Genetic or Inherited Condition



# New York State 2-1-1



Regional Resource Guide  
of the Children and Youth with Special  
Health Care Needs (CYSHCN) Project

**Agency Name:** New York State 2-1-1

**Agency Description:** 2-1-1 helps people assess their needs and links them directly to the resources that will help. The DD Info Link is an online, searchable database that provides detailed information specifically for people with intellectual and developmental disabilities, their families and service providers.

**Phone Number:** 2-1-1

**Email Address:**

**Website:** <http://211nys.org/disability-services>

**Counties Served:** State-Wide

**Content Categories:** Government Agency Information & Referral

**Conditions Covered:** Developmental Delay Other Mental Health Condition Learning Difficulty Speech or Language Disorder Attention-Deficit/Hyperactivity Disorder (ADHD) Allergies Anxiety Arthritis Asthma Autism Spectrum Disorder (ASD) Behavioral / Conduct Problem Blood Disorders Cerebral Palsy (CP) Cystic Fibrosis (CF) Depression Diabetes Down Syndrome Epilepsy / Seizure Disorder Genetic or Inherited Condition Brain Injury, Concussion, or Head Injury Deafness or Problems with Hearing Heart Condition Intellectual Disability Migraines Spina Bifida Other Substance Use Disorder Tourette Syndrome (TS) Blindness or Problems with Seeing

# New York State Association of Independent Schools (NYSAIS): Special Education



Regional Resource Guide  
of the Children and Youth with Special  
Health Care Needs (CYSHCN) Project

**Agency Name:** New York State Association of Independent Schools (NYSAIS): Special Education

**Agency Description:** The New York State Association of Independent Schools (NYSAIS) promotes the independence, well-being and public understanding of, and respect for, New York independent schools and serves as an accrediting body chartered by the New York State Board of Regents. NYSAIS has a searchable, online directory of special education schools.

**Phone Number:** (518) 694-5500

**Email Address:**

**Website:** [http://www.nysais.org/page.cfm?p=923&max=1000&filter\\_data7=Yes](http://www.nysais.org/page.cfm?p=923&max=1000&filter_data7=Yes)

**Counties Served:** State-Wide

**Content Categories:** Information & Referral Early Childhood & School Aged

**Conditions Covered:** Attention-Deficit/Hyperactivity Disorder (ADHD) Learning Difficulty Allergies Anxiety Arthritis Asthma Autism Spectrum Disorder (ASD) Behavioral / Conduct Problem Blood Disorders Cerebral Palsy (CP) Cystic Fibrosis (CF) Depression Developmental Delay Diabetes Down Syndrome Epilepsy / Seizure Disorder Genetic or Inherited Condition Brain Injury, Concussion, or Head Injury Deafness or Problems with Hearing Heart Condition Intellectual Disability Migraines Other Other Mental Health Condition Speech or Language Disorder Spina Bifida Substance Use Disorder Tourette Syndrome (TS) Blindness or Problems with Seeing

# New York State Children's Alliance, Inc. (NYSCA)



Regional Resource Guide  
of the Children and Youth with Special  
Health Care Needs (CYSHCN) Project

**Agency Name:** New York State Children's Alliance, Inc. (NYSCA)

**Agency Description:** The Mission of New York State Children's Alliance, Inc. (NYSCA) is to promote the development, growth, and continuation of Child Advocacy Centers (CACs) and Multidisciplinary Teams (MDTs) throughout New York State in order to provide healing and justice to abused and neglected children, and their families. CACs are child-focused facilities that help abused children heal by coordinating the investigation and treatment of child sexual abuse and providing children and families access to long-term advocacy and healthcare.

**Phone Number:** (585) 402-8086

**Email Address:**

**Website:** <http://www.nyschildrensalliance.org/>

**Counties Served:** State-Wide

**Content Categories:** Financial, Legal & Advocacy Information & Referral Care Coordination Family & Supports

**Conditions Covered:** Anxiety Asthma Blood Disorders Cerebral Palsy (CP) Cystic Fibrosis (CF) Depression Developmental Delay Diabetes Down Syndrome Genetic or Inherited Condition Brain Injury, Concussion, or Head Injury Deafness or Problems with Hearing Heart Condition Intellectual Disability Learning Difficulty Migraines Other Mental Health Condition Speech or Language Disorder Spina Bifida Substance Use Disorder Tourette Syndrome (TS) Blindness or Problems with Seeing Other Attention-Deficit/Hyperactivity Disorder (ADHD) Arthritis Autism Spectrum Disorder (ASD) Behavioral / Conduct Problem Epilepsy / Seizure Disorder

# New York State Commission for the Blind (NYSCB)



Regional Resource Guide  
of the Children and Youth with Special  
Health Care Needs (CYSHCN) Project

**Agency Name:** New York State Commission for the Blind (NYSCB)

**Agency Description:** The New York State Commission for the Blind (NYSCB) provides vocational rehabilitation and other direct services to legally blind New York State residents, including children, adults, and elderly persons.

**Phone Number:** (866) 871-3000

**Email Address:** ExecutiveBoardCBVH@jgb.org

**Website:** <http://ocfs.ny.gov/main/cb/district-contacts.asp>

**Counties Served:** State-Wide

**Content Categories:** Family & Supports Accessibility & Assistive Technology My Child's Condition: Disability Specific Reference  
Early Childhood & School Aged Transitioning to Adulthood (Youth) Medical, Dental & Behavioral Health

**Conditions Covered:** Blindness or Problems with Seeing Deafness or Problems with Hearing

# New York State Conference of Local Mental Hygiene Directors



Regional Resource Guide  
of the Children and Youth with Special  
Health Care Needs (CYSHCN) Project

**Agency Name:** New York State Conference of Local Mental Hygiene Directors

**Agency Description:** The Conference has the responsibility of meeting the needs of individuals and families affected by mental illness, substance use disorder and/or developmental disability in their communities. The 'Contact local mental hygiene departments' page allows you to find the specific information about the local governmental unit in your county.

**Phone Number:** (518) 462-9422

**Email Address:**

**Website:** [http://www.clmhd.org/contact\\_local\\_mental\\_hygiene\\_departments/](http://www.clmhd.org/contact_local_mental_hygiene_departments/)

**Counties Served:** State-Wide

**Content Categories:** Information & Referral, Care Coordination, Government Agency

**Conditions Covered:** Attention-Deficit/Hyperactivity Disorder (ADHD), Autism Spectrum Disorder (ASD), Cerebral Palsy (CP), Brain Injury, Concussion, or Head Injury, Depression, Developmental Delay, Intellectual Disability, Genetic or Inherited Condition, Learning Difficulty, Anxiety, Substance Use Disorder, Down Syndrome, Deafness or Problems with Hearing, Other Mental Health Condition, Tourette Syndrome (TS), Speech or Language Disorder, Blindness or Problems with Seeing

# New York State Department of Health, Wadsworth Center: Specialty Care Centers



Regional Resource Guide  
of the Children and Youth with Special  
Health Care Needs (CYSHCN) Project

**Agency Name:** New York State Department of Health, Wadsworth Center: Specialty Care Centers

**Agency Description:** Lists specialty care centers for Inherited Metabolic Disorder, Severe Combined Immunodeficiency, Cystic Fibrosis, Endocrine Disorder, Hemoglobinopathy, Neuromuscular issues. Health care providers at these specialized care centers are experienced in treating infants with one or a group of the disorders detected by NYS newborn screening.

**Phone Number:** (518) 473-7552

**Email Address:** nbsinfo@health.ny.gov

**Website:** <http://www.wadsworth.org/programs/newborn/screening/specialty-care->

**Counties Served:** State-Wide

**Content Categories:** Medical, Dental & Behavioral Health Information & Referral My Child's Condition: Disability Specific Reference

**Conditions Covered:** Genetic or Inherited Condition Allergies Cystic Fibrosis (CF) Diabetes Blood Disorders Other

# New York State Department of Health: Children and Youth with Special Health Care Needs (CYSHCN) Program



Regional Resource Guide  
of the Children and Youth with Special  
Health Care Needs (CYSHCN) Project

**Agency Name:** New York State Department of Health: Children and Youth with Special Health Care Needs (CYSHCN) Program

**Agency Description:** The New York State Children and Youth with Special Health Care Needs (CYSHCN) Program seeks to improve the system of care for children with special health care needs from birth to 21 years of age and their families. The Program helps to shape public policy so families can get the best health care for their children.

**Phone Number:** (518) 474-1961

**Email Address:**

**Website:** [http://www.health.ny.gov/community/special\\_needs](http://www.health.ny.gov/community/special_needs)

**Counties Served:** State-Wide

**Content Categories:** Accessibility & Assistive Technology, Care Coordination, Community Living & Recreation, Financial, Legal & Advocacy, Information & Referral, Medical, Dental & Behavioral Health, Transitioning to Adulthood (Youth), Government Agency, Early Childhood & School Aged, Family & Supports

**Conditions Covered:** Attention-Deficit/Hyperactivity Disorder (ADHD), Allergies, Anxiety, Arthritis, Autism Spectrum Disorder (ASD), Asthma, Behavioral / Conduct Problem, Blood Disorders, Cerebral Palsy (CP), Cystic Fibrosis (CF), Depression, Developmental Delay, Diabetes, Down Syndrome, Epilepsy / Seizure Disorder, Genetic or Inherited Condition, Brain Injury, Concussion, or Head Injury, Deafness or Problems with Hearing, Heart Condition, Intellectual Disability, Migraines, Other Mental Health Condition, Speech or Language Disorder, Spina Bifida, Substance Use Disorder, Tourette Syndrome (TS), Blindness or Problems with Seeing, Other, Learning Difficulty

# New York State Department of Health: Growing Up Healthy Hotline (GUHH)



Regional Resource Guide  
of the Children and Youth with Special  
Health Care Needs (CYSHCN) Project

**Agency Name:** New York State Department of Health: Growing Up Healthy Hotline (GUHH)

**Agency Description:** The Growing Up Healthy Hotline helps pregnant and parenting people in New York State find the help they need. Help is available in many areas, including health care and children's special needs.  
Call the Hotline anytime: 1-800-522-5006  
TTY (TeleTYpe): 1-800-655-1789

**Phone Number:** (800) 522-5006

**Email Address:**

**Website:** [http://www.health.ny.gov/community/pregnancy/health\\_care/prenatal/guh.htm](http://www.health.ny.gov/community/pregnancy/health_care/prenatal/guh.htm)

**Counties Served:** State-Wide

**Content Categories:** Government Agency Information & Referral Medical, Dental & Behavioral Health

**Conditions Covered:** Developmental Delay Other Mental Health Condition Learning Difficulty Speech or Language Disorder  
Attention-Deficit/Hyperactivity Disorder (ADHD) Allergies Anxiety Arthritis Asthma Autism Spectrum Disorder (ASD)  
Behavioral / Conduct Problem Blood Disorders Cerebral Palsy (CP) Cystic Fibrosis (CF) Depression Diabetes  
Down Syndrome Epilepsy / Seizure Disorder Genetic or Inherited Condition Brain Injury, Concussion, or Head Injury  
Deafness or Problems with Hearing Heart Condition Intellectual Disability Migraines Spina Bifida Other  
Substance Use Disorder Tourette Syndrome (TS) Blindness or Problems with Seeing



# New York State Department of Health: Physician Profile



Regional Resource Guide  
of the Children and Youth with Special  
Health Care Needs (CYSHCN) Project

**Agency Name:** New York State Department of Health: Physician Profile

**Agency Description:** This web site was created after former Governor George Pataki signed the New York Patient Health Information and Quality Improvement Act of 2000 to make it possible for all citizens of New York to get information about physicians (doctors).

**Phone Number:** (888) 338-6999

**Email Address:**

**Website:** [http://www.nydoctorprofile.com/dispatch?action=display\\_search\\_parameters](http://www.nydoctorprofile.com/dispatch?action=display_search_parameters)

**Counties Served:** State-Wide

**Content Categories:** Government Agency Information & Referral Medical, Dental & Behavioral Health

**Conditions Covered:** Developmental Delay Other Mental Health Condition Learning Difficulty Speech or Language Disorder Attention-Deficit/Hyperactivity Disorder (ADHD) Allergies Anxiety Arthritis Asthma Autism Spectrum Disorder (ASD) Behavioral / Conduct Problem Blood Disorders Cerebral Palsy (CP) Cystic Fibrosis (CF) Depression Diabetes Down Syndrome Epilepsy / Seizure Disorder Genetic or Inherited Condition Brain Injury, Concussion, or Head Injury Deafness or Problems with Hearing Heart Condition Intellectual Disability Migraines Spina Bifida Other Substance Use Disorder Tourette Syndrome (TS) Blindness or Problems with Seeing

# New York State Department of Health: Special Education Services



Regional Resource Guide  
of the Children and Youth with Special  
Health Care Needs (CYSHCN) Project

**Agency Name:** New York State Department of Health: Special Education Services

**Agency Description:** Children ages 3-21 with disabilities who live in New York State are eligible. Students thought to have a disability are referred to a multidisciplinary team (e.g., teachers, psychologists, and therapists) called the Committee on Preschool Special Education or the Committee on Special Education. The Committee arranges for an evaluation of the student's abilities and needs. Based on evaluation results, the committee decides if the student is eligible to receive special education services and programs.

**Phone Number:**

**Email Address:**

**Website:** [http://www.health.ny.gov/publications/0548/special\\_education\\_services.htm](http://www.health.ny.gov/publications/0548/special_education_services.htm)

**Counties Served:** State-Wide

**Content Categories:** Government Agency Information & Referral

**Conditions Covered:** Developmental Delay Other Mental Health Condition Learning Difficulty Speech or Language Disorder Attention-Deficit/Hyperactivity Disorder (ADHD) Allergies Anxiety Arthritis Asthma Autism Spectrum Disorder (ASD) Behavioral / Conduct Problem Blood Disorders Cerebral Palsy (CP) Cystic Fibrosis (CF) Depression Diabetes Down Syndrome Epilepsy / Seizure Disorder Genetic or Inherited Condition Brain Injury, Concussion, or Head Injury Deafness or Problems with Hearing Heart Condition Intellectual Disability Migraines Spina Bifida Other Substance Use Disorder Tourette Syndrome (TS) Blindness or Problems with Seeing

# New York State Developmental Disabilities Planning Council (DDPC)



Regional Resource Guide  
of the Children and Youth with Special  
Health Care Needs (CYSHCN) Project

**Agency Name:** New York State Developmental Disabilities Planning Council (DDPC)

**Agency Description:** The DDPC works to improve the lives of people with intellectual and developmental disabilities by funding projects related to health and wellness, education, transportation, housing, life skills and more.

**Phone Number:** (518) 486-7505

**Email Address:** [Information@ddpc.ny.gov](mailto:Information@ddpc.ny.gov)

**Website:** <http://ddpc.ny.gov/>

**Counties Served:** State-Wide

**Content Categories:** Accessibility & Assistive Technology, Family & Supports, Financial, Legal & Advocacy, Information & Referral, Government Agency

**Conditions Covered:** Developmental Delay, Learning Difficulty, Intellectual Disability, Cerebral Palsy (CP), Down Syndrome, Autism Spectrum Disorder (ASD), Genetic or Inherited Condition, Epilepsy / Seizure Disorder, Attention-Deficit/Hyperactivity Disorder (ADHD), Blindness or Problems with Seeing, Speech or Language Disorder, Tourette Syndrome (TS), Deafness or Problems with Hearing

# New York State Early Intervention Program (EIP)



Regional Resource Guide  
of the Children and Youth with Special  
Health Care Needs (CYSHCN) Project

**Agency Name:** New York State Early Intervention Program (EIP)

**Agency Description:** The New York State Early Intervention Program offers a variety of therapeutic and support services to eligible infants and toddlers with disabilities and their families. To be eligible for services, children must be under 3 years of age and have a confirmed disability or established developmental delay, as defined by the State, in one or more of the following areas of development: physical, cognitive, communication, social-emotional, and/or adaptive. Municipal/County Contacts for the Early Intervention Program can be found here:  
[https://www.health.ny.gov/community/infants\\_children/early\\_intervention/county\\_eip.htm](https://www.health.ny.gov/community/infants_children/early_intervention/county_eip.htm)

**Phone Number:** (518) 473-7016

**Email Address:** [beipub@health.ny.gov](mailto:beipub@health.ny.gov)

**Website:** [http://www.health.ny.gov/community/infants\\_children/early\\_intervention/](http://www.health.ny.gov/community/infants_children/early_intervention/)

**Counties Served:** State-Wide

**Content Categories:** Accessibility & Assistive Technology, Care Coordination, Community Living & Recreation, Financial, Legal & Advocacy, Information & Referral, Medical, Dental & Behavioral Health, Government Agency, Early Childhood & School Aged, Family & Supports

**Conditions Covered:** Attention-Deficit/Hyperactivity Disorder (ADHD), Allergies, Anxiety, Arthritis, Autism Spectrum Disorder (ASD), Asthma, Behavioral / Conduct Problem, Blood Disorders, Cerebral Palsy (CP), Cystic Fibrosis (CF), Developmental Delay, Diabetes, Down Syndrome, Epilepsy / Seizure Disorder, Genetic or Inherited Condition, Brain Injury, Concussion, or Head Injury, Deafness or Problems with Hearing, Heart Condition, Intellectual Disability, Other Mental Health Condition, Speech or Language Disorder, Spina Bifida, Blindness or Problems with Seeing, Other, Learning Difficulty, Depression, Migraines, Substance Use Disorder, Tourette Syndrome (TS)

# New York State Education Department (NYSED): Special Education Approved Schools



Regional Resource Guide  
of the Children and Youth with Special  
Health Care Needs (CYSHCN) Project

**Agency Name:** New York State Education Department (NYSED): Special Education Approved Schools

**Agency Description:** NYSED provides lists of approved schools in New York State, which can be filtered by location. Features, approved Preschool Special Education Programs, approved Private, Special Act, State-Operated, and State-Supported Schools in New York State, and information related to the Justice Center for Residential Schools.

**Phone Number:** (518) 474-3862

**Email Address:** NYSEDP12@nysed.gov

**Website:** <http://www.p12.nysed.gov/specialed/appschools.html>

**Counties Served:** State-Wide

**Content Categories:** Early Childhood & School Aged Information & Referral

**Conditions Covered:** Developmental Delay Other Mental Health Condition Learning Difficulty Speech or Language Disorder Attention-Deficit/Hyperactivity Disorder (ADHD) Allergies Anxiety Arthritis Asthma Autism Spectrum Disorder (ASD) Behavioral / Conduct Problem Blood Disorders Cerebral Palsy (CP) Cystic Fibrosis (CF) Depression Diabetes Down Syndrome Epilepsy / Seizure Disorder Genetic or Inherited Condition Brain Injury, Concussion, or Head Injury Deafness or Problems with Hearing Heart Condition Intellectual Disability Migraines Spina Bifida Other Substance Use Disorder Tourette Syndrome (TS) Blindness or Problems with Seeing

# New York State Independent Living Council (NYSILC)



Regional Resource Guide  
of the Children and Youth with Special  
Health Care Needs (CYSHCN) Project

**Agency Name:** New York State Independent Living Council (NYSILC)

**Agency Description:** The mission of the New York State Independent Living Council, Inc. (NYSILC) is to promote independent living for people with disabilities across New York State, in partnership with the network of community-based Centers for Independent Living (CILs). Independent Living is a peer-based model run and supported by people with disabilities, with the goal of ensuring access to the services needed to improve quality of life in the community. A CIL directory can be found on the website.

**Phone Number:** (518) 427-1060

**Email Address:**

**Website:** <http://nysilc.org/>

**Counties Served:** State-Wide

**Content Categories:** Community Living & Recreation Financial, Legal & Advocacy Information & Referral Family & Supports

**Conditions Covered:** Attention-Deficit/Hyperactivity Disorder (ADHD) Allergies Anxiety Arthritis Autism Spectrum Disorder (ASD) Asthma Behavioral / Conduct Problem Blood Disorders Cerebral Palsy (CP) Cystic Fibrosis (CF) Depression Developmental Delay Diabetes Down Syndrome Epilepsy / Seizure Disorder Genetic or Inherited Condition Brain Injury, Concussion, or Head Injury Deafness or Problems with Hearing Heart Condition Intellectual Disability Migraines Other Mental Health Condition Speech or Language Disorder Spina Bifida Substance Use Disorder Tourette Syndrome (TS) Blindness or Problems with Seeing Other Learning Difficulty

# New York State Justice Center for the Protection of People with Special Needs



Regional Resource Guide  
of the Children and Youth with Special  
Health Care Needs (CYSHCN) Project

**Agency Name:** New York State Justice Center for the Protection of People with Special Needs

**Agency Description:** The Justice Center for the Protection of People With Special Needs was created to restore public trust in the institutions and individuals charged with caring for vulnerable populations by protecting all people's health, safety, and dignity with special needs. The agency operates a toll-free hotline 24 hours a day, seven days a week, for receiving reports of allegations of abuse and neglect: (855) 373-2122.

**Phone Number:** (518) 549-0200

**Email Address:** [webmaster@justicecenter.ny.gov](mailto:webmaster@justicecenter.ny.gov)

**Website:** <http://www.justicecenter.ny.gov/>

**Counties Served:** State-Wide

**Content Categories:** Financial, Legal & Advocacy Government Agency Information & Referral Accessibility & Assistive Technology Family & Supports

**Conditions Covered:** Allergies Anxiety Arthritis Asthma Attention-Deficit/Hyperactivity Disorder (ADHD) Autism Spectrum Disorder (ASD) Behavioral / Conduct Problem Blindness or Problems with Seeing Blood Disorders Brain Injury, Concussion, or Head Injury Cerebral Palsy (CP) Cystic Fibrosis (CF) Deafness or Problems with Hearing Depression Developmental Delay Diabetes Down Syndrome Epilepsy / Seizure Disorder Genetic or Inherited Condition Heart Condition Intellectual Disability Learning Difficulty Migraines Other Other Mental Health Condition Speech or Language Disorder Spina Bifida Substance Use Disorder Tourette Syndrome (TS)

# New York State Justice Center for the Protection of People With Special Needs: Technology Related Assistance for Individuals



Regional Resource Guide  
of the Children and Youth with Special  
Health Care Needs (CYSHCN) Project

**Agency Name:** New York State Justice Center for the Protection of People With Special Needs: Technology Related Assistance for Individuals with Disabilities (TRAID) Program

**Agency Description:** The TRAID Program supports a system that responds to the individual needs of people with disabilities who need assistive technology. The TRAID Program helps people learn about, obtain, and be able to use assistive technology services and devices which meet their needs.

**Phone Number:** (800) 624-4143

**Email Address:**

**Website:** <http://www.justicecenter.ny.gov/traid-program>

**Counties Served:** State-Wide

**Content Categories:** Accessibility & Assistive Technology Information & Referral Financial, Legal & Advocacy Family & Supports

**Conditions Covered:** Attention-Deficit/Hyperactivity Disorder (ADHD) Allergies Anxiety Arthritis Autism Spectrum Disorder (ASD) Asthma Behavioral / Conduct Problem Blood Disorders Cerebral Palsy (CP) Cystic Fibrosis (CF) Depression Developmental Delay Diabetes Down Syndrome Epilepsy / Seizure Disorder Genetic or Inherited Condition Brain Injury, Concussion, or Head Injury Deafness or Problems with Hearing Heart Condition Intellectual Disability Migraines Other Mental Health Condition Speech or Language Disorder Spina Bifida Substance Use Disorder Tourette Syndrome (TS) Blindness or Problems with Seeing Other Learning Difficulty



# New York State Office for People With Developmental Disabilities (OPWDD)



Regional Resource Guide  
of the Children and Youth with Special  
Health Care Needs (CYSHCN) Project

**Agency Name:** New York State Office for People With Developmental Disabilities (OPWDD)

**Agency Description:** The New York State Office for People With Developmental Disabilities (OPWDD) is responsible for coordinating services for New Yorkers with developmental disabilities and neurological impairments. We provide services directly and through a network of approximately 600 nonprofit service providing agencies, with about 80 percent of services provided by the private nonprofits and 20 percent provided by state-run services.

**Phone Number:** (518) 473-9689

**Email Address:**

**Website:** <http://opwdd.ny.gov/>

**Counties Served:** State-Wide

**Content Categories:** Early Childhood & School Aged Government Agency Financial, Legal & Advocacy Family & Supports  
Accessibility & Assistive Technology Care Coordination Medical, Dental & Behavioral Health Information & Referral  
Community Living & Recreation Transitioning to Adulthood (Youth)

**Conditions Covered:** Attention-Deficit/Hyperactivity Disorder (ADHD) Autism Spectrum Disorder (ASD) Behavioral / Conduct Problem  
Blood Disorders Cerebral Palsy (CP) Cystic Fibrosis (CF) Brain Injury, Concussion, or Head Injury Developmental Delay  
Diabetes Down Syndrome Epilepsy / Seizure Disorder Genetic or Inherited Condition  
Deafness or Problems with Hearing Heart Condition Intellectual Disability Learning Difficulty Migraines Other

# New York State Office for People With Developmental Disabilities (OPWDD): Statewide Family Support Services Committee (FSS)



Regional Resource Guide  
of the Children and Youth with Special  
Health Care Needs (CYSHCN) Project

**Agency Name:** New York State Office for People With Developmental Disabilities (OPWDD): Statewide Family Support Services Committee (FSS)

**Agency Description:** The Statewide Family Support Services Committee is made up of one representative from each of the nineteen local Family Support Services Advisory Councils and advises OPWDD regarding families' support needs and the design, implementation and monitoring of Family Support Services.

**Phone Number:** (866) 946-9733

**Email Address:** [info@opwdd.ny.gov](mailto:info@opwdd.ny.gov)

**Website:** <http://opwdd.ny.gov/statewide-family-support-services-committee-fss>

**Counties Served:** State-Wide

**Content Categories:** Family & Supports Government Agency

**Conditions Covered:** Autism Spectrum Disorder (ASD) Developmental Delay Cerebral Palsy (CP) Down Syndrome Epilepsy / Seizure Disorder Intellectual Disability Attention-Deficit/Hyperactivity Disorder (ADHD) Tourette Syndrome (TS) Speech or Language Disorder Behavioral / Conduct Problem Brain Injury, Concussion, or Head Injury Genetic or Inherited Condition Cystic Fibrosis (CF) Diabetes Deafness or Problems with Hearing Other Mental Health Condition Learning Difficulty Blindness or Problems with Seeing Depression Other Spina Bifida

# New York State Office of Addiction Services and Supports (NYS OASAS)



Regional Resource Guide  
of the Children and Youth with Special  
Health Care Needs (CYSHCN) Project

**Agency Name:** New York State Office of Addiction Services and Supports (NYS OASAS)

**Agency Description:** OASAS is the single designated state agency responsible for the coordination of state-federal relations in the area of addiction services. Our mission is to improve the lives of New Yorkers by leading a comprehensive system of addiction services for prevention, treatment, and recovery. Available addiction treatment can be found using the NYS OASAS Treatment Availability Dashboard at [www.FindAddictionTreatment.ny.gov](http://www.FindAddictionTreatment.ny.gov).

**Phone Number:** (518) 457-8299

**Email Address:** [communications@oasas.ny.gov](mailto:communications@oasas.ny.gov)

**Website:** <http://oasas.ny.gov/>

**Counties Served:** State-Wide

**Content Categories:** Medical, Dental & Behavioral Health Government Agency Information & Referral Transitioning to Adulthood (Youth)  
My Child's Condition: Disability Specific Reference

**Conditions Covered:** Substance Use Disorder

# New York State Office of Children and Family Services (OCFS)



Regional Resource Guide  
of the Children and Youth with Special  
Health Care Needs (CYSHCN) Project

**Agency Name:** New York State Office of Children and Family Services (OCFS)

**Agency Description:** The Office of Children and Family Services (OCFS) serves New York's public by promoting the safety, permanency and well-being of our children, families and communities. OCFS offers numerous services in a wide variety of programs, including child care and child welfare, prevention, residential programs for youth, and services for adolescents, older adults, and New Yorkers who are legally blind. OCFS has regional offices and Local Departments of Social Services.

**Phone Number:** (800) 342-3720

**Email Address:** [info@ocfs.ny.gov](mailto:info@ocfs.ny.gov)

**Website:** <http://ocfs.ny.gov/main/>

**Counties Served:** State-Wide

**Content Categories:** Accessibility & Assistive Technology, Care Coordination, Community Living & Recreation, Financial, Legal & Advocacy, Information & Referral, Medical, Dental & Behavioral Health, Transitioning to Adulthood (Youth), Government Agency

**Conditions Covered:** Attention-Deficit/Hyperactivity Disorder (ADHD), Allergies, Anxiety, Arthritis, Autism Spectrum Disorder (ASD), Asthma, Behavioral / Conduct Problem, Blood Disorders, Cerebral Palsy (CP), Cystic Fibrosis (CF), Depression, Developmental Delay, Diabetes, Down Syndrome, Epilepsy / Seizure Disorder, Genetic or Inherited Condition, Brain Injury, Concussion, or Head Injury, Deafness or Problems with Hearing, Heart Condition, Intellectual Disability, Migraines, Other Mental Health Condition, Speech or Language Disorder, Spina Bifida, Substance Use Disorder, Tourette Syndrome (TS), Blindness or Problems with Seeing, Other, Learning Difficulty

# New York State Office of Mental Health (OMH): Program Directory



Regional Resource Guide  
of the Children and Youth with Special  
Health Care Needs (CYSHCN) Project

**Agency Name:** New York State Office of Mental Health (OMH): Program Directory

**Agency Description:** The New York State Office of Mental Health (OMH) program directory allows you to search for mental health programs by county, program category or subcategory; view program details including program name, address and phone number; and, click on any county on the map to view all of the programs in that county.

**Phone Number:** (844) 891-1786

**Email Address:**

**Website:** <http://my.omh.ny.gov/bi/pd/saw.dll?PortalPages>

**Counties Served:** State-Wide

**Content Categories:** Government Agency Information & Referral

**Conditions Covered:** Anxiety Depression Other Mental Health Condition Substance Use Disorder

# New York State Parenting Education Partnership (NYSPEP)



Regional Resource Guide  
of the Children and Youth with Special  
Health Care Needs (CYSHCN) Project

**Agency Name:** New York State Parenting Education Partnership (NYSPEP)

**Agency Description:** NYSPEP's mission is to promote and improve parenting education, in order to enhance parenting skills, knowledge and behavior. Community Cafes is one of our tools to advance family engagement and community-level, cross-systems communications with the hope of increasing reciprocity within these relationships; infusing cross-systems learning with parent and caregiver perspective; and building communities' capacity for action that strengthens families.

**Phone Number:** (518) 880-3592

**Email Address:**

**Website:** <http://nyspep.org/>

**Counties Served:** State-Wide

**Content Categories:** Accessibility & Assistive Technology, Community Living & Recreation, Financial, Legal & Advocacy, Information & Referral, Transitioning to Adulthood (Youth), Family & Supports, Early Childhood & School Aged

**Conditions Covered:** Attention-Deficit/Hyperactivity Disorder (ADHD), Allergies, Anxiety, Arthritis, Autism Spectrum Disorder (ASD), Asthma, Behavioral / Conduct Problem, Blood Disorders, Cerebral Palsy (CP), Cystic Fibrosis (CF), Depression, Developmental Delay, Diabetes, Down Syndrome, Epilepsy / Seizure Disorder, Genetic or Inherited Condition, Brain Injury, Concussion, or Head Injury, Deafness or Problems with Hearing, Heart Condition, Intellectual Disability, Migraines, Other Mental Health Condition, Speech or Language Disorder, Spina Bifida, Substance Use Disorder, Tourette Syndrome (TS), Blindness or Problems with Seeing, Other, Learning Difficulty

# New York State Talking Book and Braille Library (TBBL)



Regional Resource Guide  
of the Children and Youth with Special  
Health Care Needs (CYSHCN) Project

**Agency Name:** New York State Talking Book and Braille Library (TBBL)

**Agency Description:** The Talking Book and Braille Library (TBBL) lends braille and audiobooks and magazines, and special playback equipment to residents of the 55 upstate counties of New York State who are unable to read printed materials because of a visual or physical disability.

**Phone Number:** (800) 342-3688

**Email Address:** [tbbl@nysed.gov](mailto:tbbl@nysed.gov)

**Website:** <http://www.nysl.nysed.gov/tbbl/>

## Counties Served:

Albany County Allegany County Broome County Cattaraugus County Cayuga County Chautauqua County  
Chemung County Chenango County Clinton County Columbia County Cortland County Delaware County  
Dutchess County Erie County Essex County Franklin County Fulton County Genesee County Greene County

## Content Categories:

Early Childhood & School Aged My Child's Condition: Disability Specific Reference Family & Supports  
Accessibility & Assistive Technology Government Agency

## Conditions Covered:

Blindness or Problems with Seeing Learning Difficulty Developmental Delay Arthritis Cerebral Palsy (CP)  
Brain Injury, Concussion, or Head Injury Genetic or Inherited Condition Intellectual Disability Other Spina Bifida

# Nurturing Dyslexics



Regional Resource Guide  
of the Children and Youth with Special  
Health Care Needs (CYSHCN) Project

**Agency Name:** Nurturing Dyslexics

**Agency Description:** Nurturing Dyslexics supports dyslexic children and their families through the shared journey of dyslexia. Nurturing Dyslexics has two initiatives: (1) Nurturing Dyslexia resources and (2) Dystinct Magazine. Nurturing Dyslexics resources are specifically designed to help struggling readers. Dystinct Magazine is a resource of inspiration and expertise for the families and educators of children with learning difficulties.

**Phone Number:**

**Email Address:** [hello@nurturingdyslexics.com](mailto:hello@nurturingdyslexics.com)

**Website:** <http://nurturingdyslexics.com/>

**Counties Served:** State-Wide

**Content Categories:** Family & Supports Information & Referral Early Childhood & School Aged

**Conditions Covered:** Learning Difficulty Other Intellectual Disability



# NY Connects



Regional Resource Guide  
of the Children and Youth with Special  
Health Care Needs (CYSHCN) Project

**Agency Name:** NY Connects

**Agency Description:** NY Connects provides information and assistance related to long-term services and supports in New York State for people of all ages or with any type of disability. NY Connects uses a searchable directory for programs, providers, and services in your area. NY Connects staff can help link you to long-term services and supports, such as home care, transportation and meals.

**Phone Number:** (800) 342-9871

**Email Address:**

**Website:** <http://www.nyconnects.ny.gov/contact-us>

**Counties Served:** State-Wide

**Content Categories:** Information & Referral Government Agency

**Conditions Covered:** Attention-Deficit/Hyperactivity Disorder (ADHD) Allergies Anxiety Arthritis Autism Spectrum Disorder (ASD) Asthma Behavioral / Conduct Problem Blood Disorders Cerebral Palsy (CP) Cystic Fibrosis (CF) Depression Developmental Delay Diabetes Down Syndrome Epilepsy / Seizure Disorder Genetic or Inherited Condition Brain Injury, Concussion, or Head Injury Deafness or Problems with Hearing Heart Condition Intellectual Disability Migraines Other Mental Health Condition Speech or Language Disorder Spina Bifida Substance Use Disorder Tourette Syndrome (TS) Blindness or Problems with Seeing Other

# NYS Multiple Systems Navigator



Regional Resource Guide  
of the Children and Youth with Special  
Health Care Needs (CYSHCN) Project

**Agency Name:** NYS Multiple Systems Navigator

**Agency Description:** The primary goal of the Navigating Multiple Systems initiative is to provide easily accessible resources, service information and tools to assist youth, parents, family members/caregivers, and front-line staff currently struggling to effectively and efficiently navigate multiple human service systems – creating a web-based, ‘one-stop-shop’ for user-friendly, accurate and up-to-date disability information and tools.

**Phone Number:**

**Email Address:** [msnavigator@ccf.ny.gov](mailto:msnavigator@ccf.ny.gov)

**Website:** <http://www.msnavigator.org/>

**Counties Served:** State-Wide

**Content Categories:** Information & Referral

**Conditions Covered:** Attention-Deficit/Hyperactivity Disorder (ADHD) Allergies Anxiety Arthritis Autism Spectrum Disorder (ASD) Asthma Behavioral / Conduct Problem Blood Disorders Cerebral Palsy (CP) Cystic Fibrosis (CF) Depression Developmental Delay Diabetes Down Syndrome Epilepsy / Seizure Disorder Genetic or Inherited Condition Brain Injury, Concussion, or Head Injury Deafness or Problems with Hearing Heart Condition Intellectual Disability Migraines Other Mental Health Condition Speech or Language Disorder Spina Bifida Substance Use Disorder Tourette Syndrome (TS) Blindness or Problems with Seeing Other Learning Difficulty

# Office for People With Developmental Disabilities (OPWDD): Front Door



Regional Resource Guide  
of the Children and Youth with Special  
Health Care Needs (CYSHCN) Project

**Agency Name:** Office for People With Developmental Disabilities (OPWDD): Front Door

**Agency Description:** The Front Door is the way OPWDD connects you to the services you want and need. Once you enter, a person-centered planning process begins, which helps you learn about and access service options that take your needs and desires into consideration. There are multiple Front Door offices across New York State.

**Phone Number:** (866) 946-9733

**Email Address:** [info@opwdd.ny.gov](mailto:info@opwdd.ny.gov)

**Website:** <http://opwdd.ny.gov/contact-us#access-services-through-front-door>

**Counties Served:** State-Wide

**Content Categories:** Government Agency Information & Referral Care Coordination

**Conditions Covered:** Developmental Delay Autism Spectrum Disorder (ASD) Down Syndrome Behavioral / Conduct Problem Cerebral Palsy (CP) Epilepsy / Seizure Disorder Brain Injury, Concussion, or Head Injury Attention-Deficit/Hyperactivity Disorder (ADHD) Other Mental Health Condition Genetic or Inherited Condition Learning Difficulty Intellectual Disability Blindness or Problems with Seeing Other Anxiety Cystic Fibrosis (CF) Depression Deafness or Problems with Hearing Speech or Language Disorder Spina Bifida Arthritis Asthma Allergies

# Office for People With Developmental Disabilities (OPWDD): Provider Directory



Regional Resource Guide  
of the Children and Youth with Special  
Health Care Needs (CYSHCN) Project

**Agency Name:** Office for People With Developmental Disabilities (OPWDD): Provider Directory

**Agency Description:** OPWDD offers individualized, person-centered supports to children and young adults aged birth to 21 who are OPWDD-eligible with a qualifying diagnosis. OPWDD services can be provided in addition to supports received through Early Intervention (EI), the education system, and the Office for Children and Family Services (OCFS), which are the primary systems serving children with disabilities in New York State.

**Phone Number:** (866) 946-9733

**Email Address:** [info@opwdd.ny.gov](mailto:info@opwdd.ny.gov)

**Website:** <http://providerdirectory.opwdd.ny.gov/>

**Counties Served:** State-Wide

**Content Categories:** Government Agency Information & Referral

**Conditions Covered:** Developmental Delay Autism Spectrum Disorder (ASD) Down Syndrome Behavioral / Conduct Problem Cerebral Palsy (CP) Epilepsy / Seizure Disorder Brain Injury, Concussion, or Head Injury Attention-Deficit/Hyperactivity Disorder (ADHD) Other Mental Health Condition Genetic or Inherited Condition Learning Difficulty Intellectual Disability Blindness or Problems with Seeing Other Anxiety Cystic Fibrosis (CF) Depression Deafness or Problems with Hearing Speech or Language Disorder Spina Bifida Arthritis Asthma Allergies

# Okayso: Expert Advice



Regional Resource Guide  
of the Children and Youth with Special  
Health Care Needs (CYSHCN) Project

**Agency Name:** Okayso: Expert Advice

**Agency Description:** When you're having a personal problem, you need advice from real people you can trust. okayso is an app that gives you access to experts you can't reach any other way to get support and information whenever you need it. From sex and dating to identity and more, we're here for you. The app is free and you can communicate anonymously.

**Phone Number:**

**Email Address:**

**Website:** <http://okayso.co/>

**Counties Served:** State-Wide

**Content Categories:** Accessibility & Assistive Technology Information & Referral Transitioning to Adulthood (Youth) Community Living & Recreation Family & Supports

**Conditions Covered:** Anxiety Other Mental Health Condition Depression

# Open the Lid



Regional Resource Guide  
of the Children and Youth with Special  
Health Care Needs (CYSHCN) Project

**Agency Name:** Open the Lid

**Agency Description:** We provide web-based courses, strategies & community created by a Certified Special Education Teacher and coach. Our goal is to empower individuals to move from where they are to where they want to be with simple strategies and supportive people.

**Phone Number:** (607) 339-8092

**Email Address:** support@openthelid.com

**Website:** <http://www.openthelid.com/>

**Counties Served:** State-Wide

**Content Categories:** Community Living & Recreation, Family & Supports, Information & Referral, Financial, Legal & Advocacy, Transitioning to Adulthood (Youth)

**Conditions Covered:** Allergies, Anxiety, Arthritis, Asthma, Attention-Deficit/Hyperactivity Disorder (ADHD), Autism Spectrum Disorder (ASD), Behavioral / Conduct Problem, Blood Disorders, Brain Injury, Concussion, or Head Injury, Cerebral Palsy (CP), Cystic Fibrosis (CF), Depression, Developmental Delay, Diabetes, Down Syndrome, Epilepsy / Seizure Disorder, Genetic or Inherited Condition, Deafness or Problems with Hearing, Heart Condition, Intellectual Disability, Learning Difficulty, Migraines, Other, Other Mental Health Condition, Speech or Language Disorder, Spina Bifida, Substance Use Disorder, Tourette Syndrome (TS), Blindness or Problems with Seeing

# Organization for Autism Research (OAR)



Regional Resource Guide  
of the Children and Youth with Special  
Health Care Needs (CYSHCN) Project

**Agency Name:** Organization for Autism Research (OAR)

**Agency Description:** OAR uses science to address the social, educational, and treatment concerns of self-advocates, parents, autism professionals, and caregivers. We disseminate new and useful information to as many members of the autism community as possible, and direct all research and program initiatives toward enhancing the quality of life for individuals with autism.

**Phone Number:** (866) 366-9710

**Email Address:** [info@researchautism.org](mailto:info@researchautism.org)

**Website:** <http://researchautism.org/>

**Counties Served:** [State-Wide](#)

**Content Categories:** [Information & Referral](#) [Family & Supports](#) [Financial, Legal & Advocacy](#)

**Conditions Covered:** [Autism Spectrum Disorder \(ASD\)](#)

# Parent Advocacy Coalition for Educational Rights (PACER) Center



Regional Resource Guide  
of the Children and Youth with Special  
Health Care Needs (CYSHCN) Project

**Agency Name:** Parent Advocacy Coalition for Educational Rights (PACER) Center

**Agency Description:** PACER is dedicated to improving the lives of children and youth with special health care needs. Services include: support, assistive technology, education and helpful information, and links towards independent living. The website has a variety of helpful videos and guides and useful information on laws and people's rights. All services are provided free of charge.

**Phone Number:** (952) 838-9000

**Email Address:** [pacer@pacer.org](mailto:pacer@pacer.org)

**Website:** <http://www.pacer.org/>

**Counties Served:** State-Wide

**Content Categories:** Accessibility & Assistive Technology, Early Childhood & School Aged, Family & Supports, Information & Referral, Community Living & Recreation, Care Coordination, Financial, Legal & Advocacy, Transitioning to Adulthood (Youth), Medical, Dental & Behavioral Health

**Conditions Covered:** Attention-Deficit/Hyperactivity Disorder (ADHD), Allergies, Anxiety, Arthritis, Asthma, Autism Spectrum Disorder (ASD), Behavioral / Conduct Problem, Blood Disorders, Brain Injury, Concussion, or Head Injury, Cerebral Palsy (CP), Cystic Fibrosis (CF), Depression, Developmental Delay, Diabetes, Down Syndrome, Epilepsy / Seizure Disorder, Genetic or Inherited Condition, Deafness or Problems with Hearing, Heart Condition, Intellectual Disability, Learning Difficulty, Migraines, Other, Other Mental Health Condition, Spina Bifida, Speech or Language Disorder, Tourette Syndrome (TS), Blindness or Problems with Seeing, Substance Use Disorder



# Parent to Parent of New York State



Regional Resource Guide  
of the Children and Youth with Special  
Health Care Needs (CYSHCN) Project

**Agency Name:** Parent to Parent of New York State

**Agency Description:** Parent to Parent of New York State is a statewide not for profit organization established to support and connect families of individuals with special needs. We have several offices located throughout New York State staffed by Regional Coordinators who are parents or close relatives of individuals with special needs.

**Phone Number:** (800) 405-8818

**Email Address:** [info@ptopnys.org](mailto:info@ptopnys.org)

**Website:** <http://parenttoparentnys.org>

**Counties Served:** State-Wide

**Content Categories:** Family & Supports Information & Referral

**Conditions Covered:** Attention-Deficit/Hyperactivity Disorder (ADHD) Autism Spectrum Disorder (ASD) Behavioral / Conduct Problem Cerebral Palsy (CP) Other Allergies Anxiety Arthritis Asthma Blood Disorders Cystic Fibrosis (CF) Depression Developmental Delay Diabetes Down Syndrome Epilepsy / Seizure Disorder Genetic or Inherited Condition Brain Injury, Concussion, or Head Injury Deafness or Problems with Hearing Heart Condition Intellectual Disability Learning Difficulty Migraines Other Mental Health Condition Speech or Language Disorder Spina Bifida Substance Use Disorder Tourette Syndrome (TS) Blindness or Problems with Seeing

# Parents of Blind Children of New York (POBCNY)



Regional Resource Guide  
of the Children and Youth with Special  
Health Care Needs (CYSHCN) Project

**Agency Name:** Parents of Blind Children of New York (POBCNY)

**Agency Description:** The POBCNY is a parent advocacy group working to improve the lives of blind children within the state of New York. It is our mission to elevate the quality of education for blind children, to affect our children's access to services, to create opportunities in theatre and the arts, in sports and recreation, and to raise the level of expectation that those around us have of our children.

**Phone Number:** (917) 475-6642

**Email Address:** [pobcny@gmail.com](mailto:pobcny@gmail.com)

**Website:** <http://www.nypobc.org/>

**Counties Served:** [State-Wide](#)

**Content Categories:** [Family & Supports](#) [Information & Referral](#) [Transitioning to Adulthood \(Youth\)](#) [Early Childhood & School Aged](#) [Community Living & Recreation](#) [Financial, Legal & Advocacy](#) [My Child's Condition: Disability Specific Reference](#) [Accessibility & Assistive Technology](#)

**Conditions Covered:** [Blindness or Problems with Seeing](#)

# Primary Ciliary Dyskinesia (PCD) Foundation



Regional Resource Guide  
of the Children and Youth with Special  
Health Care Needs (CYSHCN) Project

**Agency Name:** Primary Ciliary Dyskinesia (PCD) Foundation

**Agency Description:** The PCD Foundation envisions a world free from illness and early death due to primary ciliary dyskinesia (PCD), and in order to carry out that vision, we strive to do the following by 1) improving diagnosis, quality of life, and prognosis through research, 2) educating & supporting patient, scientific, and medical communities and 3) raising awareness of PCD.

**Phone Number:** (844) 287-3723

**Email Address:** [info@pcdfoundation.org](mailto:info@pcdfoundation.org)

**Website:** <http://pcdfoundation.org/>

**Counties Served:** State-Wide

**Content Categories:** Information & Referral My Child's Condition: Disability Specific Reference Financial, Legal & Advocacy

**Conditions Covered:** Genetic or Inherited Condition

# RespectAbility



Regional Resource Guide  
of the Children and Youth with Special  
Health Care Needs (CYSHCN) Project

**Agency Name:** RespectAbility

**Agency Description:** RespectAbility works collaboratively with employers, entertainment leaders, governors, policy makers, educators, self-advocates, non-profits, faith-based organizations, philanthropists and the media to fight stigmas and advance opportunities.

**Phone Number:** (202) 517-6272

**Email Address:** [info@respectability.org](mailto:info@respectability.org)

**Website:** <http://www.respectability.org>

**Counties Served:** State-Wide

**Content Categories:** Financial, Legal & Advocacy

**Conditions Covered:** Attention-Deficit/Hyperactivity Disorder (ADHD) Allergies Anxiety Arthritis Autism Spectrum Disorder (ASD) Asthma Behavioral / Conduct Problem Blood Disorders Cerebral Palsy (CP) Cystic Fibrosis (CF) Depression Developmental Delay Diabetes Down Syndrome Epilepsy / Seizure Disorder Genetic or Inherited Condition Brain Injury, Concussion, or Head Injury Deafness or Problems with Hearing Heart Condition Intellectual Disability Migraines Other Mental Health Condition Speech or Language Disorder Spina Bifida Substance Use Disorder Tourette Syndrome (TS) Blindness or Problems with Seeing Other Learning Difficulty

# Rising New York Road Runners (NYRR): Wheelchair Training Program



Regional Resource Guide  
of the Children and Youth with Special  
Health Care Needs (CYSHCN) Project

**Agency Name:** Rising New York Road Runners (NYRR): Wheelchair Training Program

**Agency Description:** Rising New York Road Runners Wheelchair Training Program is a free, year-round program for youth with physical disabilities ages 6 to 21. The program offers weekly training sessions, in-school resources, and competitive events on the road and track, regardless of experience or prior NYRR affiliation. This program is for children who are dependent on a wheelchair to run. This includes kids with hypertonia, ataxia and/or athetosis, impaired muscle power, impaired passive muscle range of motion, and/or limb deficiency and those who do not wish to run with prosthetics.

**Phone Number:** (855) 569-6977

**Email Address:** risingnyrr@nyrr.org

**Website:** <http://www.nyrr.org/Youth/Youth-Initiatives/Rising-New-York-Road-Runners->

**Counties Served:** State-Wide

**Content Categories:** Early Childhood & School Aged, Community Living & Recreation, Accessibility & Assistive Technology, Transitioning to Adulthood (Youth), Information & Referral

**Conditions Covered:** Arthritis, Brain Injury, Concussion, or Head Injury, Cerebral Palsy (CP), Cystic Fibrosis (CF), Epilepsy / Seizure Disorder, Genetic or Inherited Condition, Heart Condition, Other, Spina Bifida

# Self-Advocacy Association of New York State, Inc. (SANYS)



Regional Resource Guide  
of the Children and Youth with Special  
Health Care Needs (CYSHCN) Project

**Agency Name:** Self-Advocacy Association of New York State, Inc. (SANYS)

**Agency Description:** The Self-Advocacy Association of New York State, Inc. (SANYS) is an organization founded and led by people with developmental disabilities, for people with developmental disabilities. We promote the awareness and recognition of our civil rights and responsibilities, which include opportunities and choices of equal citizenship. Our goal is to help self-advocates build the skill and courage needed to speak up for themselves and others.

**Phone Number:** (518) 382-1454

**Email Address:**

**Website:** <http://sanys.org/regions/>

**Counties Served:** State-Wide

**Content Categories:** Transitioning to Adulthood (Youth) Financial, Legal & Advocacy Family & Supports

**Conditions Covered:** Developmental Delay Intellectual Disability Learning Difficulty Attention-Deficit/Hyperactivity Disorder (ADHD) Blindness or Problems with Seeing Cerebral Palsy (CP) Deafness or Problems with Hearing Down Syndrome Epilepsy / Seizure Disorder Autism Spectrum Disorder (ASD) Cystic Fibrosis (CF) Anxiety Speech or Language Disorder Other Mental Health Condition

# Sesame Street in Communities



Regional Resource Guide  
of the Children and Youth with Special  
Health Care Needs (CYSHCN) Project

**Agency Name:** Sesame Street in Communities

**Agency Description:** Sesame Street in Communities unites communities, foster families' and kids' resilience, nurture their physical and mental health, and provide critical early learning opportunities. Here, you'll find hundreds of bilingual multi-media tools to help kids and families enrich and expand their knowledge during the early years of birth through six, a critical window for brain development.

**Phone Number:**

**Email Address:** [Communities@sesame.org](mailto:Communities@sesame.org)

**Website:** <http://sesamestreetincommunities.org/>

**Counties Served:** [State-Wide](#)

**Content Categories:** [Family & Supports](#) [Financial, Legal & Advocacy](#) [Information & Referral](#) [Early Childhood & School Aged](#)  
[Community Living & Recreation](#)

**Conditions Covered:** [Autism Spectrum Disorder \(ASD\)](#) [Asthma](#) [Speech or Language Disorder](#) [Substance Use Disorder](#) [Anxiety](#) [Depression](#)  
[Learning Difficulty](#) [Other Mental Health Condition](#) [Developmental Delay](#) [Behavioral / Conduct Problem](#)  
[Attention-Deficit/Hyperactivity Disorder \(ADHD\)](#) [Intellectual Disability](#)

# Sick Kids [Need] Involved People of New York (SKIP of NY)



Regional Resource Guide  
of the Children and Youth with Special  
Health Care Needs (CYSHCN) Project

**Agency Name:** Sick Kids [Need] Involved People of New York (SKIP of NY)

**Agency Description:** SKIP of NY helps medically fragile and/or developmentally disabled children in the state of New York get (and stay!) home from hospitals and institutions to live with their families. SKIP acts as a free medical concierge connecting children to the help they need such as nursing care, medical equipment, home modifications, and educational and recreational programs.

**Phone Number:** (212) 268-5999

**Email Address:** [info@skipofny.org](mailto:info@skipofny.org)

**Website:** <http://skipofny.org/>

**Counties Served:** State-Wide

**Content Categories:** Financial, Legal & Advocacy Accessibility & Assistive Technology Care Coordination Community Living & Recreation Family & Supports Information & Referral

**Conditions Covered:** Developmental Delay Intellectual Disability Autism Spectrum Disorder (ASD) Cerebral Palsy (CP) Blood Disorders Brain Injury, Concussion, or Head Injury Heart Condition Spina Bifida Other Cystic Fibrosis (CF)



# Sickle Cell Disease Association of America, Inc. (SCDAA)



Regional Resource Guide  
of the Children and Youth with Special  
Health Care Needs (CYSHCN) Project

**Agency Name:** Sickle Cell Disease Association of America, Inc. (SCDAA)

**Agency Description:** The mission of SCDAA is: To advocate for people affected by sickle cell conditions and empower community-based organizations to maximize quality of life and raise public consciousness while advancing the search for a universal cure. The Queens Sickle Cell Advocacy Network, Inc. (QSCAN) and Sickle Cell/Thalassemia Patients Network (SCTPN) are member organizations in New York.

**Phone Number:**

**Email Address:** [info@sicklecelldisease.org](mailto:info@sicklecelldisease.org)

**Website:** <http://sicklecelldisease.net/>

**Counties Served:** State-Wide

**Content Categories:** Financial, Legal & Advocacy Family & Supports Care Coordination Information & Referral  
My Child's Condition: Disability Specific Reference Community Living & Recreation

**Conditions Covered:** Blood Disorders

# Special Olympics New York (SONY)



Regional Resource Guide  
of the Children and Youth with Special  
Health Care Needs (CYSHCN) Project

**Agency Name:** Special Olympics New York (SONY)

**Agency Description:** Our mission is to provide year-round sports training and athletic competition in a variety of Olympic-style sports for all children and adults with intellectual disabilities giving them continuing opportunities to develop physical fitness, demonstrate courage, experience joy, and participate in a sharing of skills and friendship with their families, Special Olympics athletes and the community. We cover many areas across New York.

**Phone Number:** (518) 388-0790

**Email Address:**

**Website:** <http://www.specialolympics.org/programs/united-states/new-york?locale=en>

**Counties Served:** State-Wide

**Content Categories:** Community Living & Recreation Family & Supports

**Conditions Covered:** Arthritis Attention-Deficit/Hyperactivity Disorder (ADHD) Cerebral Palsy (CP) Cystic Fibrosis (CF) Autism Spectrum Disorder (ASD) Brain Injury, Concussion, or Head Injury Blood Disorders Developmental Delay Down Syndrome Epilepsy / Seizure Disorder Genetic or Inherited Condition Heart Condition Deafness or Problems with Hearing Intellectual Disability Learning Difficulty Other Other Mental Health Condition Spina Bifida Blindness or Problems with Seeing Tourette Syndrome (TS)

# Spina Bifida Association of Northeastern New York (SBANENY)



Regional Resource Guide  
of the Children and Youth with Special  
Health Care Needs (CYSHCN) Project

**Agency Name:** Spina Bifida Association of Northeastern New York (SBANENY)

**Agency Description:** Spina Bifida Association of Northeastern New York (SBANENY) focuses on building a better and brighter future for all those impacted by Spina Bifida. SBANENY provides information and education, referrals, support, advocacy, systems navigation, and programming for individuals and families living with Spina Bifida.

**Phone Number:** (518) 399-9151

**Email Address:** [admin@sbaneny.org](mailto:admin@sbaneny.org)

**Website:** <http://www.sbaneny.org/>

**Counties Served:** State-Wide

**Content Categories:** Family & Supports My Child's Condition: Disability Specific Reference Information & Referral  
Transitioning to Adulthood (Youth) Financial, Legal & Advocacy

**Conditions Covered:** Spina Bifida

**Agency Name:** Starbridge, Inc.

**Agency Description:** We partner with people who have disabilities, their families, and others who support them, to achieve success in education, employment, and healthy living. Services include: education, transition planning, employment, family supports, self-direction, home and living.

**Phone Number:** (585) 546-1700

**Email Address:** [info@starbridgeinc.org](mailto:info@starbridgeinc.org)

**Website:** <http://www.starbridgeinc.org/>

**Counties Served:**

Monroe County Yates County Wayne County Ontario County Livingston County Albany County Allegany County  
Broome County Cattaraugus County Cayuga County Chautauqua County Chemung County Chenango County  
Clinton County Columbia County Cortland County Delaware County Dutchess County Erie County Essex County

**Content Categories:**

Care Coordination Family & Supports Financial, Legal & Advocacy Transitioning to Adulthood (Youth)  
Early Childhood & School Aged

**Conditions Covered:**

Autism Spectrum Disorder (ASD) Behavioral / Conduct Problem Cerebral Palsy (CP) Developmental Delay  
Epilepsy / Seizure Disorder Intellectual Disability Speech or Language Disorder Tourette Syndrome (TS)  
Blindness or Problems with Seeing Learning Difficulty Spina Bifida Attention-Deficit/Hyperactivity Disorder (ADHD)  
Cystic Fibrosis (CF) Down Syndrome Brain Injury, Concussion, or Head Injury Genetic or Inherited Condition  
Deafness or Problems with Hearing

# State Public Health Autism Resource Center (SPHARC)



Regional Resource Guide  
of the Children and Youth with Special  
Health Care Needs (CYSHCN) Project

**Agency Name:** State Public Health Autism Resource Center (SPHARC)

**Agency Description:** SPHARC is a comprehensive, national web-based resource center intended to provide ongoing technical assistance and facilitate cross-state learning to increase the capacity of states, particularly Title V programs, in developing and implementing systems of care for children and youth with autism spectrum disorders and other developmental disabilities (ASD/DD). SPHARC can support families in locating resources and making connections at the state or national level. SPHARC Resource Search: <http://www.amchp.org/programsandtopics/CYSHCN/projects/spharc/resources/Pages/default.aspx>

**Phone Number:** (202) 266-3042

**Email Address:**

**Website:** <http://www.amchp.org/programsandtopics/CYSHCN/projects/spharc/Pages/default.aspx>

**Counties Served:** State-Wide

**Content Categories:** Financial, Legal & Advocacy Information & Referral My Child's Condition: Disability Specific Reference Family & Supports

**Conditions Covered:** Autism Spectrum Disorder (ASD) Developmental Delay Intellectual Disability Learning Difficulty Speech or Language Disorder

# Supportive Housing Network of New York (SHNNY)



Regional Resource Guide  
of the Children and Youth with Special  
Health Care Needs (CYSHCN) Project

**Agency Name:** Supportive Housing Network of New York (SHNNY)

**Agency Description:** The Supportive Housing Network of New York (SHNNY) is focused on supportive housing. Supportive housing hopes to end homelessness for vulnerable people: individuals and families dealing with mental illness, trauma/abuse, addiction, and chronic illness including HIV/AIDS. Our work includes advocacy, policy analysis, training, technical assistance, and public education.

**Phone Number:** (646) 619-9640

**Email Address:** [info@shnny.org](mailto:info@shnny.org)

**Website:** <http://shnny.org/>

**Counties Served:** State-Wide

**Content Categories:** Financial, Legal & Advocacy Family & Supports Information & Referral Community Living & Recreation  
Transitioning to Adulthood (Youth)

**Conditions Covered:** Behavioral / Conduct Problem Depression Developmental Delay Genetic or Inherited Condition  
Other Mental Health Condition Substance Use Disorder Other Anxiety Cystic Fibrosis (CF) Blood Disorders  
Diabetes

# The Arc New York



Regional Resource Guide  
of the Children and Youth with Special  
Health Care Needs (CYSHCN) Project

**Agency Name:** The Arc New York

**Agency Description:** The Arc New York's mission is to advocate and provide support and services to people with intellectual, developmental, and other disabilities, emphasizing choice and community engagement. You can find additional local chapters in New York here: <https://thearc.org/chapter/the-arc-new-york/>. A second email for The Arc New York is: [info@nysarc.org](mailto:info@nysarc.org).

**Phone Number:** (518) 439-8311

**Email Address:** [Info@TheArcNY.org](mailto:Info@TheArcNY.org)

**Website:** <http://www.thearcnyc.org/find-your-chapter>

**Counties Served:** State-Wide

**Content Categories:** Family & Supports Financial, Legal & Advocacy Information & Referral Transitioning to Adulthood (Youth)  
Early Childhood & School Aged Community Living & Recreation

**Conditions Covered:** Allergies Anxiety Arthritis Asthma Attention-Deficit/Hyperactivity Disorder (ADHD) Autism Spectrum Disorder (ASD)  
Behavioral / Conduct Problem Blood Disorders Brain Injury, Concussion, or Head Injury Cerebral Palsy (CP)  
Cystic Fibrosis (CF) Depression Developmental Delay Diabetes Down Syndrome Epilepsy / Seizure Disorder  
Genetic or Inherited Condition Deafness or Problems with Hearing Heart Condition Intellectual Disability  
Learning Difficulty Migraines Other Other Mental Health Condition Speech or Language Disorder Spina Bifida  
Substance Use Disorder Tourette Syndrome (TS) Blindness or Problems with Seeing

# The M.O.R.G.A.N. Project



Regional Resource Guide  
of the Children and Youth with Special  
Health Care Needs (CYSHCN) Project

**Agency Name:** The M.O.R.G.A.N. Project

**Agency Description:** The M.O.R.G.A.N. Project is a national, community-based organization of volunteers dedicated to promoting awareness and facilitating support of parents caring for their children/young adults with special health care needs, thereby enhancing the Quality-of-Life for these special families.

**Phone Number:** (321) 506-2707

**Email Address:** [info@themorganproject.org](mailto:info@themorganproject.org)

**Website:** <http://themorganproject.org>

**Counties Served:** State-Wide

**Content Categories:** Financial, Legal & Advocacy Information & Referral Family & Supports

**Conditions Covered:** Attention-Deficit/Hyperactivity Disorder (ADHD) Allergies Anxiety Arthritis Autism Spectrum Disorder (ASD) Asthma Behavioral / Conduct Problem Blood Disorders Cerebral Palsy (CP) Cystic Fibrosis (CF) Depression Developmental Delay Diabetes Down Syndrome Epilepsy / Seizure Disorder Genetic or Inherited Condition Brain Injury, Concussion, or Head Injury Deafness or Problems with Hearing Heart Condition Intellectual Disability Migraines Other Mental Health Condition Speech or Language Disorder Spina Bifida Substance Use Disorder Tourette Syndrome (TS) Blindness or Problems with Seeing Other Learning Difficulty



# The Trevor Project



Regional Resource Guide  
of the Children and Youth with Special  
Health Care Needs (CYSHCN) Project

**Agency Name:** The Trevor Project

**Agency Description:** The Trevor Project provides crisis intervention and suicide prevention services to lesbian, gay, bisexual, transgender, queer & questioning youth. If you are thinking about suicide or are feeling alone and need someone to talk to, please call the Trevor Lifeline at 1-866-488-7386 for immediate help. It's free, confidential, and available 24/7.

**Phone Number:** (212) 695-8650

**Email Address:** [info@thetrevorproject.org](mailto:info@thetrevorproject.org)

**Website:** <http://www.thetrevorproject.org/>

**Counties Served:** [State-Wide](#)

**Content Categories:** [Accessibility & Assistive Technology](#) [Family & Supports](#) [Information & Referral](#) [Financial, Legal & Advocacy](#)  
[Community Living & Recreation](#) [Medical, Dental & Behavioral Health](#)

**Conditions Covered:** [Anxiety](#) [Behavioral / Conduct Problem](#) [Depression](#) [Other Mental Health Condition](#) [Substance Use Disorder](#)

**Agency Name:** Think College

**Agency Description:** Think College is a national organization dedicated to developing, expanding, and improving inclusive higher education options for people with intellectual disability. The Think College directory includes information on college programs in New York for students with intellectual disability:  
[https://thinkcollege.net/college-search?f%5B0%5D=tc\\_state\\_province%3ANew%20York](https://thinkcollege.net/college-search?f%5B0%5D=tc_state_province%3ANew%20York)

**Phone Number:** (617) 287-4300

**Email Address:** [thinkcollege@umb.edu](mailto:thinkcollege@umb.edu)

**Website:** <http://thinkcollege.net/>

**Counties Served:** State-Wide

**Content Categories:** Information & Referral Transitioning to Adulthood (Youth)

**Conditions Covered:** Down Syndrome Intellectual Disability Learning Difficulty Autism Spectrum Disorder (ASD) Cerebral Palsy (CP) Genetic or Inherited Condition

# Through the Looking Glass (TLG)



Regional Resource Guide  
of the Children and Youth with Special  
Health Care Needs (CYSHCN) Project

**Agency Name:** Through the Looking Glass (TLG)

**Agency Description:** Through the Looking Glass (TLG) is a nationally recognized center that has pioneered research, training, and services for families in which a child, parent or grandparent has a disability or medical issue.

**Phone Number:** (800) 644-2666

**Email Address:** [tlg@lookingglass.org](mailto:tlg@lookingglass.org)

**Website:** <http://www.lookingglass.org>

**Counties Served:** State-Wide

**Content Categories:** Accessibility & Assistive Technology, Care Coordination, Community Living & Recreation, Financial, Legal & Advocacy, Information & Referral, Medical, Dental & Behavioral Health, Transitioning to Adulthood (Youth), Family & Supports

**Conditions Covered:** Attention-Deficit/Hyperactivity Disorder (ADHD), Allergies, Anxiety, Arthritis, Autism Spectrum Disorder (ASD), Asthma, Behavioral / Conduct Problem, Blood Disorders, Cerebral Palsy (CP), Cystic Fibrosis (CF), Depression, Developmental Delay, Diabetes, Down Syndrome, Epilepsy / Seizure Disorder, Genetic or Inherited Condition, Brain Injury, Concussion, or Head Injury, Deafness or Problems with Hearing, Heart Condition, Intellectual Disability, Migraines, Other Mental Health Condition, Speech or Language Disorder, Spina Bifida, Substance Use Disorder, Tourette Syndrome (TS), Blindness or Problems with Seeing, Other, Learning Difficulty

# Tourette Association of America (TAA)



Regional Resource Guide  
of the Children and Youth with Special  
Health Care Needs (CYSHCN) Project

**Agency Name:** Tourette Association of America (TAA)

**Agency Description:** The Tourette Association of America (TAA) serves the community, and works to raise awareness, advance research, and provide ongoing support to patients and families impacted by Tourette Syndrome and Tic Disorders. TAA has multiple chapters in New York.

**Phone Number:** (888) 486-8738

**Email Address:** support@tourette.org

**Website:** <http://tourette.org/resources/local-support/>

**Counties Served:** State-Wide

**Content Categories:** Family & Supports My Child's Condition: Disability Specific Reference Financial, Legal & Advocacy Information & Referral  
Community Living & Recreation

**Conditions Covered:** Tourette Syndrome (TS)

**Agency Name:** TransCen, Inc.

**Agency Description:** TransCen, Inc., is a non-profit organization dedicated to improving education and employment success of youth and young adults with disabilities. TransCen's webinar trainings translate research and effective practices into useable, practical information. Our webinars assist vocational rehabilitation staff, policymakers, researchers, individuals with disabilities and their families, educators, practitioners, service providers, and employers.

**Phone Number:** (301) 424-2002

**Email Address:** [inquiries@transcen.org](mailto:inquiries@transcen.org)

**Website:** <http://www.transcen.org/>

**Counties Served:** State-Wide

**Content Categories:** Transitioning to Adulthood (Youth) Accessibility & Assistive Technology Family & Supports Information & Referral

**Conditions Covered:** Allergies Anxiety Arthritis Asthma Attention-Deficit/Hyperactivity Disorder (ADHD) Autism Spectrum Disorder (ASD) Behavioral / Conduct Problem Blood Disorders Brain Injury, Concussion, or Head Injury Cerebral Palsy (CP) Cystic Fibrosis (CF) Depression Developmental Delay Diabetes Down Syndrome Epilepsy / Seizure Disorder Genetic or Inherited Condition Deafness or Problems with Hearing Heart Condition Intellectual Disability Learning Difficulty Migraines Other Other Mental Health Condition Spina Bifida Speech or Language Disorder Blindness or Problems with Seeing Tourette Syndrome (TS) Substance Use Disorder

# Tri-County Care



Regional Resource Guide  
of the Children and Youth with Special  
Health Care Needs (CYSHCN) Project

**Agency Name:** Tri-County Care

**Agency Description:** Tri-County Care serves thousands of individuals throughout New York State, empowering people with developmental disabilities to lead a full and meaningful life of their choosing. Through holistic, comprehensive, and culturally sensitive care management, we serve as lifetime care advocates for people with I-DD and their families.

**Phone Number:** (844) 504-8400

**Email Address:** [info@tricountycare.org](mailto:info@tricountycare.org)

**Website:** <http://www.tricountycare.org/>

## Counties Served:

Warren County Washington County Saratoga County Schenectady County Albany County Rensselaer County  
Greene County Columbia County Ulster County Dutchess County Putnam County Sullivan County  
Rockland County Westchester County Orange County Nassau County Suffolk County

## Content Categories:

Care Coordination Family & Supports Information & Referral

## Conditions Covered:

Developmental Delay Intellectual Disability Attention-Deficit/Hyperactivity Disorder (ADHD)  
Autism Spectrum Disorder (ASD) Behavioral / Conduct Problem Tourette Syndrome (TS) Speech or Language Disorder  
Cerebral Palsy (CP) Blindness or Problems with Seeing Brain Injury, Concussion, or Head Injury  
Genetic or Inherited Condition Deafness or Problems with Hearing Learning Difficulty

# U.S. Department of Labor, Office of Disability Employment Policy: Disability.gov



Regional Resource Guide  
of the Children and Youth with Special  
Health Care Needs (CYSHCN) Project

**Agency Name:** U.S. Department of Labor, Office of Disability Employment Policy: Disability.gov

**Agency Description:** Disability.gov is the federal government website for comprehensive information about disability-related programs, services, policies, laws and regulations. The site links to thousands of resources from many different federal government agencies, as well as state and local governments and nonprofit organizations across the country.

**Phone Number:** (866) 487-2365

**Email Address:**

**Website:** <http://disability.gov>

**Counties Served:** State-Wide

**Content Categories:** Government Agency Information & Referral

**Conditions Covered:** Attention-Deficit/Hyperactivity Disorder (ADHD) Allergies Anxiety Arthritis Autism Spectrum Disorder (ASD) Asthma Behavioral / Conduct Problem Blood Disorders Cerebral Palsy (CP) Cystic Fibrosis (CF) Depression Developmental Delay Diabetes Down Syndrome Epilepsy / Seizure Disorder Genetic or Inherited Condition Brain Injury, Concussion, or Head Injury Deafness or Problems with Hearing Heart Condition Intellectual Disability Migraines Other Mental Health Condition Speech or Language Disorder Spina Bifida Substance Use Disorder Tourette Syndrome (TS) Blindness or Problems with Seeing Other Learning Difficulty

# Understanding Our Differences (UOD)



Regional Resource Guide  
of the Children and Youth with Special  
Health Care Needs (CYSHCN) Project

**Agency Name:** Understanding Our Differences (UOD)

**Agency Description:** Understanding Our Differences (UOD) uses a hands-on, participatory curriculum to foster respect, acceptance, and inclusion for people of all abilities in elementary schools and communities at large.

**Phone Number:** (617) 559-6075

**Email Address:** [info@understandingourdifferences.org](mailto:info@understandingourdifferences.org)

**Website:** <http://understandingourdifferences.org>

**Counties Served:** State-Wide

**Content Categories:** Community Living & Recreation Financial, Legal & Advocacy Information & Referral Transitioning to Adulthood (Youth) Family & Supports Early Childhood & School Aged

**Conditions Covered:** Attention-Deficit/Hyperactivity Disorder (ADHD) Allergies Anxiety Arthritis Autism Spectrum Disorder (ASD) Asthma Behavioral / Conduct Problem Blood Disorders Cerebral Palsy (CP) Cystic Fibrosis (CF) Depression Developmental Delay Diabetes Down Syndrome Epilepsy / Seizure Disorder Genetic or Inherited Condition Brain Injury, Concussion, or Head Injury Deafness or Problems with Hearing Heart Condition Intellectual Disability Migraines Other Mental Health Condition Speech or Language Disorder Spina Bifida Substance Use Disorder Tourette Syndrome (TS) Blindness or Problems with Seeing Other Learning Difficulty



# Understood



Regional Resource Guide  
of the Children and Youth with Special  
Health Care Needs (CYSHCN) Project

**Agency Name:** Understood

**Agency Description:** Understood has programs for families, educators, and young adults that focus on empowering people who learn and think differently and those who support them. We offer customized, accessible resources and a compassionate community. Our Workplace program helps organizations across industries create inclusive workplaces..

**Phone Number:**

**Email Address:** [support@understood.org](mailto:support@understood.org)

**Website:** <http://www.understood.org/about>

**Counties Served:**

State-Wide

**Content Categories:**

Accessibility & Assistive Technology   Community Living & Recreation   Financial, Legal & Advocacy   Information & Referral  
Transitioning to Adulthood (Youth)   Family & Supports

**Conditions Covered:**

Attention-Deficit/Hyperactivity Disorder (ADHD)   Allergies   Anxiety   Arthritis   Autism Spectrum Disorder (ASD)   Asthma  
Behavioral / Conduct Problem   Blood Disorders   Cerebral Palsy (CP)   Cystic Fibrosis (CF)   Depression  
Developmental Delay   Diabetes   Down Syndrome   Epilepsy / Seizure Disorder   Genetic or Inherited Condition  
Brain Injury, Concussion, or Head Injury   Deafness or Problems with Hearing   Heart Condition   Intellectual Disability  
Migraines   Other Mental Health Condition   Speech or Language Disorder   Spina Bifida   Substance Use Disorder  
Tourette Syndrome (TS)   Blindness or Problems with Seeing   Other   Learning Difficulty

**Agency Name:** Wildwood

**Agency Description:** Wildwood provides supports and services to people of all ages with conditions described as developmental disabilities, complex learning disabilities and autism spectrum disorders. Children as young as three and adults enjoying their senior years receive supports and services in every life area in an environment where they are accepted, respected and valued.

**Phone Number:** (518) 640-3300

**Email Address:** [info@wildwoodprograms.org](mailto:info@wildwoodprograms.org)

**Website:** <http://www.wildwood.edu/>

**Counties Served:** Schenectady County

**Content Categories:** Accessibility & Assistive Technology Care Coordination Community Living & Recreation Early Childhood & School Aged Family & Supports Financial, Legal & Advocacy Information & Referral Medical, Dental & Behavioral Health Transitioning to Adulthood (Youth)

**Conditions Covered:** Allergies Anxiety Asthma Blood Disorders Cerebral Palsy (CP) Cystic Fibrosis (CF) Depression Developmental Delay Diabetes Down Syndrome Genetic or Inherited Condition Brain Injury, Concussion, or Head Injury Deafness or Problems with Hearing Heart Condition Intellectual Disability Learning Difficulty Migraines Other Mental Health Condition Speech or Language Disorder Spina Bifida Substance Use Disorder Tourette Syndrome (TS) Blindness or Problems with Seeing Other Attention-Deficit/Hyperactivity Disorder (ADHD) Arthritis Autism Spectrum Disorder (ASD) Behavioral / Conduct Problem Epilepsy / Seizure Disorder

# Wonder Baby



Regional Resource Guide  
of the Children and Youth with Special  
Health Care Needs (CYSHCN) Project

**Agency Name:** Wonder Baby

**Agency Description:** Wonder Baby is dedicated to helping parents of young children with visual impairments and children with multiple disabilities. We have a database of articles written by parents who want to share with others what they've learned about playing with and teaching a blind child, as well as links to meaningful resources and ways to connect with other families.

**Phone Number:**

**Email Address:** [help@wonderbaby.org](mailto:help@wonderbaby.org)

**Website:** <http://www.wonderbaby.org/>

**Counties Served:** [State-Wide](#)

**Content Categories:** [Family & Supports](#) [Information & Referral](#)

**Conditions Covered:** [Autism Spectrum Disorder \(ASD\)](#) [Behavioral / Conduct Problem](#) [Blindness or Problems with Seeing](#) [Developmental Delay](#) [Epilepsy / Seizure Disorder](#) [Genetic or Inherited Condition](#) [Intellectual Disability](#) [Speech or Language Disorder](#)

# Wraparound Services of the Hudson Valley



Regional Resource Guide  
of the Children and Youth with Special  
Health Care Needs (CYSHCN) Project

**Agency Name:** Wraparound Services of the Hudson Valley

**Agency Description:** Wraparound Services of the Hudson Valley partners with communities throughout the Mid-Hudson Valley to empower people with developmental disabilities to achieve their highest potential by providing innovative community, educational and residential services.

**Phone Number:** (845) 336-7235

**Email Address:** [info@wshv.org](mailto:info@wshv.org)

**Website:** <http://cpulster.org/>

**Counties Served:**

Ulster County Albany County Putnam County Rockland County Westchester County Dutchess County  
Orange County Sullivan County

**Content Categories:**

Accessibility & Assistive Technology Care Coordination Community Living & Recreation Early Childhood & School Aged  
Family & Supports Financial, Legal & Advocacy Information & Referral Medical, Dental & Behavioral Health  
Transitioning to Adulthood (Youth)

**Conditions Covered:**

Developmental Delay Attention-Deficit/Hyperactivity Disorder (ADHD) Autism Spectrum Disorder (ASD)  
Cerebral Palsy (CP) Deafness or Problems with Hearing Intellectual Disability Learning Difficulty  
Blindness or Problems with Seeing

# Wrightslaw



Regional Resource Guide  
of the Children and Youth with Special  
Health Care Needs (CYSHCN) Project

**Agency Name:** Wrightslaw

**Agency Description:** Parents, educators, advocates, and attorneys use Wrightslaw for reliable information about special education law and advocacy for children with disabilities.

**Phone Number:**

**Email Address:** [webmaster@wrightslaw.com](mailto:webmaster@wrightslaw.com)

**Website:** <http://www.wrightslaw.com/>

**Counties Served:** [State-Wide](#)

**Content Categories:** [Financial, Legal & Advocacy](#) [Information & Referral](#)

**Conditions Covered:** [Attention-Deficit/Hyperactivity Disorder \(ADHD\)](#) [Allergies](#) [Anxiety](#) [Arthritis](#) [Asthma](#) [Autism Spectrum Disorder \(ASD\)](#) [Behavioral / Conduct Problem](#) [Blood Disorders](#) [Cerebral Palsy \(CP\)](#) [Cystic Fibrosis \(CF\)](#) [Depression](#) [Developmental Delay](#) [Diabetes](#) [Down Syndrome](#) [Epilepsy / Seizure Disorder](#) [Genetic or Inherited Condition](#) [Brain Injury, Concussion, or Head Injury](#) [Deafness or Problems with Hearing](#) [Heart Condition](#) [Intellectual Disability](#) [Learning Difficulty](#) [Migraines](#) [Other](#) [Other Mental Health Condition](#) [Speech or Language Disorder](#) [Spina Bifida](#) [Substance Use Disorder](#) [Tourette Syndrome \(TS\)](#) [Blindness or Problems with Seeing](#)

# Youthhood



Regional Resource Guide  
of the Children and Youth with Special  
Health Care Needs (CYSHCN) Project

**Agency Name:** Youthhood

**Agency Description:** Youthhood is an informational site which helps youth plan for life after high school. It is a youth-designed site for youth with special health care needs. Youthhood provides easily accessible information on postsecondary education, independent living, and opportunities to achieve a successful future.

**Phone Number:** (612) 624-2097

**Email Address:** youthhood@umn.edu

**Website:** <http://www.youthhood.org/>

**Counties Served:** State-Wide

**Content Categories:** Family & Supports, Accessibility & Assistive Technology, Information & Referral, Transitioning to Adulthood (Youth), Community Living & Recreation, Financial, Legal & Advocacy

**Conditions Covered:** Allergies, Anxiety, Arthritis, Asthma, Attention-Deficit/Hyperactivity Disorder (ADHD), Autism Spectrum Disorder (ASD), Behavioral / Conduct Problem, Blood Disorders, Brain Injury, Concussion, or Head Injury, Cerebral Palsy (CP), Cystic Fibrosis (CF), Depression, Developmental Delay, Diabetes, Down Syndrome, Epilepsy / Seizure Disorder, Genetic or Inherited Condition, Deafness or Problems with Hearing, Heart Condition, Intellectual Disability, Learning Difficulty, Migraines, Other, Other Mental Health Condition, Speech or Language Disorder, Spina Bifida, Substance Use Disorder, Tourette Syndrome (TS), Blindness or Problems with Seeing